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Institute of Health  
& Wellbeing

**“I guess it’s just the fear of the unknown”: An Interpretative  
Phenomenological Analysis of the experiences of IBD patients  
transitioning from paediatric to adult care**

And Clinical Research Portfolio

**Isabelle Kolte**

(MA, MSc)

Submitted in partial fulfilment of the requirements for the degree of

Doctorate in Clinical Psychology

Institute of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

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# TABLE OF CONTENTS

	Page
Declaration of Originality	i
Word Count	ii
Acknowledgements	iii
 <b>Chapter 1: Systematic Review</b>	 1 - 30
Psychological factors associated with health-related quality of life in paediatric inflammatory bowel disease: A systematic review	
 <b>Chapter 2: Major Research Project</b>	 31 - 64
“I guess it’s just the fear of the unknown”: An Interpretative Phenomenological Analysis of the experiences of IBD patients transitioning from paediatric to adult care	
 <b>Appendices</b>	
Appendix 1: Summary of Author Guidelines for Submission to the Journal of Pediatric Gastroenterology and Nutrition	65 - 69
 <i>Systematic Review</i>	
Appendix 2: Search Strategies	70
Appendix 3: Quality Assessment Tool	71
Appendix 4: Item and Quality Ratings for Each Study	72 - 73
Appendix 5: PRISMA 2009 Checklist	74 - 75
 <i>Major Research Project</i>	
Appendix 6: Ethics and NHS R&D Approval Letters	76 - 81
Appendix 7: Research Pack: Invitation Letter, Participant Information Sheet and Participant Response Form	82 - 88
Appendix 8: Reminder Letter	89
Appendix 9: Participant Consent Form	90 - 91
Appendix 10: Interview Schedule	92 - 95
Appendix 11: Sample of Analysed Transcript	96 - 100
Appendix 12: Major Research Project Proposal	101 - 117



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## **CHAPTER ONE SYSTEMATIC REVIEW**

**Psychological factors associated with health-related quality of life  
in paediatric inflammatory bowel disease: A systematic review**

**Isabelle Kolte, MA, MSc**

Chapter word count: 6591

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Gastroenterology and Nutrition (Appendix 1, p.62)

*Submitted in partial fulfilment of the requirements  
for the degree of Doctorate in Clinical Psychology*

## ABSTRACT

*Objectives:* The aim of this systematic review was to identify and synthesise the current research investigating the psychological factors associated with health-related quality of life (HRQoL) in paediatric Inflammatory Bowel Disease (IBD). Adolescents with IBD have poorer HRQoL than healthy peers. An awareness of psychological factors that impede HRQoL may promote the consideration of psychological issues in medical care and inform multidisciplinary treatment planning.

*Methods:* A systematic search was conducted using PsycINFO, MEDLINE, EMBASE and CINAHL. Studies were screened against inclusion and exclusion criteria. A narrative synthesis of eligible studies was undertaken. Study quality was evaluated using an adapted quality assessment tool for cross-sectional studies.

*Results:* Twelve articles met the inclusion criteria. Negative associations were found between HRQoL and adolescents' psychological morbidity, caregiver depressive symptoms, parental stress, difficulties in family functioning and negative parenting styles. Positive associations were found between HRQoL and adolescents' self-esteem and positive parenting styles. Inconsistent findings were reported with regards to the link between HRQoL and adolescent coping.

*Conclusions:* The review identified a number of modifiable psychological factors associated with impaired HRQoL. Clinicians may want to consider screening for these factors and where appropriate, offer interventions to improve HRQoL outcomes. However, future research may be required to (1) establish the temporal relationships between psychological factors and HRQoL (2) replicate findings based on single studies, and (3) assess the effectiveness of interventions.

**Key Words:** adolescent, Crohn's disease, Ulcerative colitis, quality of life, psychological determinant

#### **What is Known**

- Adolescents with IBD have lower HRQoL as compared to healthy peers.
- An awareness of psychological variables may promote the consideration of psychological issues in treatment planning.

#### **What is New**

- Several modifiable psychological factors influence the HRQoL of adolescents with IBD.
- Poorer HRQoL was associated with adolescent psychological morbidity, caregiver depressive symptoms, parental stress, difficulties in family functioning and negative caregiver coping styles and parenting behaviours.

## INTRODUCTION

Inflammatory Bowel Disease (IBD) is a term used to describe two main conditions: Crohn's disease (CD) and Ulcerative colitis (UC). In a minority of cases, the type is unclear and a diagnosis of Indeterminate colitis (IC) is given. IBD is a relapsing and remitting condition that is characterised by the chronic inflammation of different parts of the digestive system. Common symptoms include abdominal pain, diarrhoea, weight loss and fatigue. There is no cure, but drug treatments are used to manage symptoms and to induce and maintain remission. In severe cases, surgery is recommended (Crohn's & Colitis UK, 2017). The incidence of paediatric-onset IBD is increasing worldwide (Benchimol et al., 2011). Up to 25% of patients develop IBD during childhood or adolescence (Kelsen & Baldassano, 2008).

IBD symptoms and treatment regimens have the potential to negatively impact adolescents' physical and psychosocial functioning (Mackner et al, 2013). The World Health Organization defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, n.d., para. 1). Health-related quality of life (HRQoL) has become an important outcome in healthcare research because it captures this broader conceptualisation of health. It is a multidimensional construct that assesses the perceived impact of a chronic medical condition on physical, psychological, and social functioning and well-being (Matza et al., 2004; Leidy et al., 1999).

Both generic and disease-specific measures are used for measuring HRQoL (Matza et al., 2004). Generic measures assess aspects of functioning that are relevant to both healthy and ill populations. Disease-specific measures consider symptoms,

functional status and treatment aspects that are relevant to specific medical conditions (Mackner et al., 2013; Matza et al., 2004). The majority of measures provide an overall score and a score by dimension. In paediatric populations, HRQoL is assessed through self-report or proxy report by caregivers (Solans et al., 2008). The IMPACT-III questionnaire is a frequently used, valid and reliable IBD-specific measure of HRQoL (Werner et al., 2013; Otley et al., 2002). The PedsQL 4.0 is a generic validated instrument for paediatric patients with chronic health conditions (Varni et al., 2001).

Data suggest that adolescents with IBD have lower HRQoL as compared to healthy peers (Mackner et al., 2013; Greenley et al., 2010). Understanding factors that lead to impaired HRQoL is clinically relevant as it may help identify subsets of at-risk adolescent IBD patients and advance effective treatment planning (Tabibian et al., 2015). Osoba and King (2005) argue that “the ultimate goal of health care is to restore or preserve functioning and well-being related to health, that is health-related quality of life”. A number of clinical, demographic and psychosocial factors have been investigated as determinants of HRQoL in paediatric and adult IBD populations (Moradkhani et al., 2013; Haapamäki et al., 2011; Cunningham et al., 2007; van der Eijk et al., 2004; Hjortswang et al., 2003). For example, disease activity has frequently been associated with reduced HRQoL in paediatric IBD (Mackner et al., 2013). A systematic review that assessed determinants of HRQoL in adult patients with CD found that factors consistently associated with reduced HRQoL included disease activity, number of relapses and hospitalisation rate. Factors found to be less consistently associated with HRQoL in adult IBD patients included sociodemographic factors like age, sex and disease type. Personality traits and psychological distress were identified as psychological determinants of HRQoL (van der Have et al., 2014). A number of psychological

correlates of HRQoL have also been examined in the paediatric IBD population (Mackner et al., 2013). However, to date, no systematic review has synthesised the available evidence. An awareness of psychological factors that result in impaired HRQoL may facilitate the consideration of psychological issues in medical care and inform effective multidisciplinary treatment planning. Thus, this review aimed to identify and synthesise the current research investigating the psychological factors associated with HRQoL in paediatric IBD patients.

## **METHODS**

### **Search Strategy**

In collaboration with a Librarian, a search strategy was designed to identify studies which examined psychological factors that are associated with HRQoL in paediatric IBD. Electronic databases (MEDLINE, PsychINFO, EMBASE and CINAHL) were searched for studies published from inception to October 20<sup>th</sup>, 2017. The search strategy combined subject headings and keywords (and their synonyms) including: 'quality of life' AND 'inflammatory bowel diseases/or ulcerative colitis/or crohn disease' AND 'adolescent/or child'. Search terms were customised to each database (Appendix 2, p.67). Reference lists from included full-text articles were searched to identify other potentially relevant studies.

### **Study Selection**

Database searches and study selection were undertaken by the author (IK). Titles and abstracts were screened and selected for full-article review if they met the following inclusion criteria:

- (1) Empirical quantitative study published in a peer-reviewed journal

- (2) Adolescent IBD patients (aged 10-19 years in accordance with WHO definition, 2013)
- (3) Examining relationships between psychological factors and HRQoL outcomes in adolescent IBD patients
- (4) English or German language article.

Studies were excluded if they met any of the following criteria:

- (1) Qualitative methodology
- (2) Not primary research
- (3) Examined only clinical or treatment-related determinants of HRQoL

All full-text articles were then reviewed by the author (IK) using the same predefined inclusion and exclusion criteria.

## **Data Extraction and Quality Appraisal**

Data relevant to the research question was systematically extracted by the author (IK). The extracted data included publication data and country of origin, study design, data analysis, sample characteristics, psychological factor and HRQoL measures and relevant results.

Study quality was assessed with a 15-item checklist that was adapted from the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (National Heart, Lung, and Blood Institute, 2014) and the Appraisal Tool for Cross-Sectional Studies (AXIS) (Downes et al., 2016) (Appendix 3, p. 68). Each item on the checklist was rated on a nominal scale; 'yes', 'no' or 'don't know' (not reported or cannot determine). The items were then divided into quality of reporting and three sources of bias: selection bias, information bias and



confounding. Like the original tools, the adapted version does not provide a numerical scale, but involves subjective assessment. Current Cochrane Collaboration guidance discourages the use of rigid checklists and quality scores and supports the assessment of risk of bias based on a combination of theoretical and empirical considerations and critical judgement (Higgins et al., 2011). Quality of reporting and risk of bias in each domain were rated as high, moderate or low. Overall study quality was rated high, when risk of bias was low in all domains and moderate when there was moderate risk of bias in at least one domain. If the risk of bias was rated as high in one or moderate in at least two domains, overall study quality was rated as low. Five papers were also quality assessed by another Trainee Clinical Psychologist, independent of the review. The overall agreement rate between assessors was 85%. Any disagreements were discussed and resolved by consensus.

## **Data Synthesis**

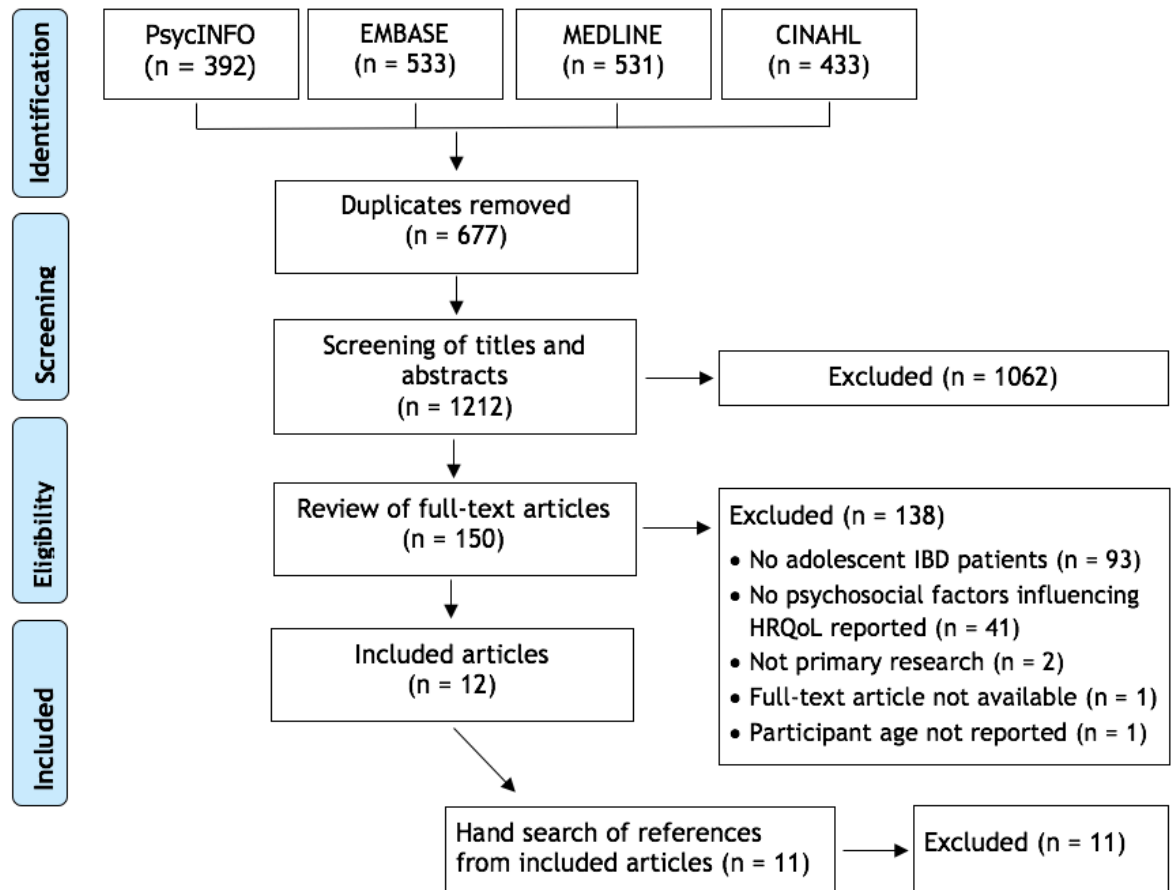
The broad nature of the research question and the heterogeneity of the psychological factors investigated in the included studies precluded meta-analysis. Therefore, a narrative synthesis was conducted. Psychological factors linked to HRQoL were clustered into conceptually and thematically related groups (e.g. psychological morbidity, stress and coping).

## **RESULTS**

The literature search yielded 1889 relevant articles (Fig.1). Removal of duplicates resulted in 1212 articles that were screened on title and abstract using the predefined inclusion and exclusion criteria. A total of 1062 articles were excluded,

leaving 150 for full-text screening. The most common reasons for exclusion were no adolescent IBD population and not examining the relationship between psychological factors and HRQoL. Twelve studies were found eligible for inclusion in the narrative synthesis (Table 1).

**Figure 1.** PRISMA Flow diagram of study selection process



## Study Characteristics

Table 1 presents the twelve studies included in the review. Eight studies originated from the USA (Reed-Knight et al., 2016; Loreaux et al., 2015; Gumidyala & Greenley, 2013; Mackner et al., 2012; Gray et al., 2011; Herzer et al., 2011a; Herzer et al., 2011b; MacPhee et al., 1998), others from Europe (Jelenova et al., 2016; Engelmann et al., 2014; de Boer et al., 2005; van der Zaag-Loonen et al., 2004). All studies presented cross-sectional data. Three studies

were part of a larger longitudinal study that examined adherence to medication in adolescents with IBD (Gray et al., 2011; Herzer et al., 2011a; Herzer et al., 2011b). Self-report measures were utilised for all HRQoL outcomes and for all but one psychological factor which was assessed through a structured psychiatric interview (Engelmann et al., 2014). Disease-specific and generic HRQoL questionnaires were used. Some studies examined the relationship between psychological variables and overall HRQoL (Jelenova et al., 2016; Reed-Knight et al., 2016; Loreaux et al., 2015; Engelmann et al., 2014; Gray et al., 2011) and others reported findings for different domains of HRQoL (Gumidyala & Greenley, 2013; Herzer et al., 2011a; Herzer et al., 2011b; De Boer et al., 2005; van der Zaag-Loonen et al., 2004). One study assessed only one HRQoL domain (school functioning) (Mackner et al., 2012) and another study used only the satisfaction with health status subscale from a generic quality of life instrument (MacPhee et al., 1998). The results were predominantly correlations and regression analysis. Two studies carried out an analysis of variance (Engelmann et al., 2014; Herzer et al., 2011a). Sample sizes varied between 27 and 86 patients and with mean ages ranging from 13.9 to 15.4 years. The majority of samples included more male than female adolescents and more participants with CD than UC. Four studies also included adolescents with IC (Loreaux et al., 2015; Mackner et al., 2012; de Boer et al., 2005; van der Zaag-Loonen et al., 2004). All but one study (de Boer et al., 2005) assessed levels of disease activity. Generally, disease activity was categorised as no activity, mild activity and moderate/severe activity and reported as percentages or number of participants in each category. The majority identified that their sample had predominantly no or mild disease activity (77% - 100%). Only one study found that 47% of their sample had moderate/severe disease activity (MacPhee et al., 1998). Studies reported findings collectively for CD, UC and IC.

**Table 1.** Summary of studies included in systematic review.

Study	Relevant Aim	Design and Sample Characteristics	Measures	Significant Results
Jelenova et al. (2016)  Czech Republic	To discover the impact of parental style on HRQoL	Cross-Sectional Correlation  N = 27 (17 CD, 10 UC) 14 male, 13 female Age (M = 15.1 ± 1.2)	Children's Report of Parent Behaviour Inventory (CRPBI) (Czech version)  KidScreen-10 Pediatric Quality of Life Inventory (PedsQL)	Significant positive correlations were found between HRQoL and positive parental behaviours and autonomous behaviours of mothers.  Significant negative correlations were found between HRQoL and hostile parental behaviours and inconsistent behaviours of fathers.
Reed-Knight et al. (2016)  USA	To examine DA, patient's internalising symptoms and caregivers' depressive symptoms as predictors of HRQoL	Cross-Sectional Multiple mediator model  N = 83 (63 CD, 20 UC) 44 male, 39 female Age (M = 14.8, SD = 2.3)	Behaviour Assessment System for Children (BASC-2) Symptom Checklist-90-Revised (SCL-90-R) Pediatric Crohn's Disease Activity Index (PCDAI) Pediatric Ulcerative Colitis Activity Index (PUCAI)  IMPACT-III	Significant negative correlations were found between HRQoL and adolescents internalising symptoms and caregiver depressive symptoms.  Adolescent internalising symptoms and caregiver depressive symptoms mediated the relationship between DA and HRQoL.  Together these three mediators accounted for 35% of the variance in HRQoL; DA alone accounted for 15%.
Loreaux et al. (2015)  USA	To examine the association of parent depression with the relation between adolescent depression and HRQoL	Cross-Sectional Hierarchical regression analysis  N = 86 (65 CD, 18 UC, 3 IC) 45 male, 41 female Age (M = 14.1, SD = 1.9)	BASC-2 (depression scale) Brief Symptom Inventory (BSI)  IMPACT-III	There was a significant negative correlation between HRQoL and adolescent and parent depression.  Parent depression significantly moderated the relationship between adolescent-reported depressive symptoms and HRQoL but only among parents reporting higher depressive symptoms.
Engelmann et al. (2014)  Germany	To compare the influence of psychiatric comorbidity and DA on HRQoL	Cross-Sectional Multi-factor analysis  N = 47 (21 CD, 26 UC) 27 male, 20 female Age (M = 15.2, SD = 1.8)	Clinical Assessment Scale of Child and Adolescent Psychopathology (CASCAP) PCDAI PUCAI  IMPACT-III EQ-5D	Adolescents with psychiatric disorders reported significantly lower HRQoL than those without, but the difference was only significant in adolescents with mild DA.  DA and psychiatric disorders together explained 30% of the variance in HRQoL.

**Table 1. (Continued)**

Study	Relevant Aim	Design and Sample Characteristics	Measures	Relevant Results
Gumidyala & Greenley (2013)  USA	To examine associations between several potential risk factors (disease-related, individual, contextual) and HRQoL	Cross-Sectional Correlations  N = 50 (43 CD, 7 UC) 29 male, 21 female Age (M = 15)	PedsQL (family impact module) Family Assessment Device General Functioning Scale (FAD) Revised Children's Depression and Anxiety Scale (RCADS)  PedsQL	The contextual risk domain (family functioning, SES) was the only domain associated with all HRQoL total and domain scores across youth and mother-reported HRQoL. It shared the greatest amount of variance with the HRQoL outcomes (up to 19%).
Mackner et al. (2012)  USA	To investigate demographic, disease and psychosocial variables as predictors of school-related QoL	Cross-Sectional Hierarchical regression analysis  N = 50 (38 CD, 4 UC, 8 IC) 31 male, 19 female Age (M = 14.69, SD = 1.92)	Child Behaviour Checklist (CBCL)  PedsQL (school functioning scale)	Hierarchical regression analysis showed that parental marital status and somatic complaints were the best predictors for school QoL.  Internalising and externalising symptoms were associated with reduced school QoL, but the association was not significant.
Gray et al. (2011)  USA	To examine the relationship among behavioural and emotional functioning and DA with HRQoL	Cross-sectional Bivariate correlation Multiple regression analyses  N = 62 (49 CD, 13 UC) 35 male, 27 female Age (M = 15.4, SD = 1.4)	The Youth Self-Report (YSR) PCDAI Lichtiger Colitis Activity Index (LCAI)  IMPACT-III	Significant negative correlations were found between HRQoL and DA, internalising symptoms and externalising symptoms.  Internalising symptoms partially mediated the relationship between DA and HRQoL reducing the effect of DA on HRQoL from 22% to 9%.
Herzer et al. (2011a)  USA	To examine the relationship between various domains of family functioning and HRQoL	Cross-sectional Multivariate analysis of variance  N = 62 (49 CD, 13 UC) 35 male, 27 female Age (M = 15.4, SD = 1.4)	FAD PCDAI LCAI  IMPACT-III	After statistically controlling for the effect of DA and IBD diagnosis, clinically elevated difficulties in several domains of family functioning had a significant negative impact on HRQoL in certain domains.  (1) Problem solving, communication and general family functioning difficulties were associated with lower social functioning (2) Communication and general family functioning were associated with lower general well-being.

**Table 1. (Continued)**

Study	Relevant Aim	Design and Sample Characteristics	Measures	Relevant Results
Herzer et al. (2011b)  USA	To examine the link between parent distress, adolescent depressive symptoms, and HRQoL	Cross-sectional Multiple regression analysis  N = 62 (49 CD, 13 UC) 35 male, 27 female Age (M = 15.4, SD = 1.4)	Pediatric Inventory for Parents (PIP-D) Children's Depression Inventory (CDI) PCDAI LCAI  IMPACT-III	Significant negative correlations were found between all HRQoL domains and adolescent depressive symptoms. Significant negative correlations were found between parent stress and HRQoL in all domains except for body image. Adolescent depressive symptoms fully mediated the relationship between parent distress and HRQoL; mediation persisted after statistically controlling for DA, IBD diagnosis and demographic factors.
De Boer et al. (2005)  Netherlands	To find out how self-esteem influences HRQoL	Cross-sectional Multiple regression analysis  N = 40 (28 CD, 9 UC, 3 IC) 19 male, 21 female Age (M = 15.2 ± 1.5)	Self-Perception Profile for Adolescents (SPPA) (Dutch version)  The Dutch Children's AZL/TNO Quality of Life Questionnaire (DUCATQOL)	Self-esteem was positively associated with HRQoL in all domains. Self-esteem was a significant predictor of HRQoL. Certain subscales of self-perception were positively associated with various HRQoL domains. Physical appearance was positively associated with HRQoL in all domains.
Van der Zaag-Loonen et al. (2004)  Netherlands	To identify which variables (coping, sociodemographic, medical) were most associated with HRQoL	Cross-sectional Multiple regression analyses  N = 65 (34 CD, 29 UC, 2 IC) 45 male, 20 female Age (M = 15.4, SD = 1.7)	The Utrecht Coping List for Adolescents (UCL-A) Cognitive Control Strategy Scale for Children (CCSS-c)  IMPACT-II (NL)	DA, predictive coping and depressive reaction pattern were associated with various HRQoL domains. Use of a predictive coping style was associated with better HRQoL. Use of a depressive reaction pattern was associated with reduced HRQoL.
MacPhee et al. (1998)  USA	To examine family and adolescent psychosocial factors that may contribute to quality of life	Cross-sectional Correlation  N = 30 (12 CD, 18 UC) 12 male, 18 female Age (M = 13.9, SD ± 12.6)	Coping Health Inventory for Parents (CHIP) Adolescent Coping Orientation for Problem Experiences (A-COPE)  Quality of Life for Adolescents and Parents (QOL) (health subscale)	Adolescent coping strategies were not significantly associated with QOL health scores. Parent coping (integrating family members, enhancing family supports and information seeking) was significantly associated with lower QOL health scores.
<b>Abbreviations:</b> Crohn's disease (CD); Cumulative risk index (CRI); DA = Disease activity; Indeterminate colitis (IC); Inflammatory Bowel Disease (IBD); Socioeconomic status (SES); Ulcerative colitis (UC)				

## **Study Quality and Methodological Strengths and Weaknesses**

The risk of bias and quality ratings for each study are summarised in Table 2. A detailed breakdown of the quality appraisal can be found in Appendix 4, p.69. Two studies were deemed of low quality (Jelenova et al., 2016; MacPhee et al., 1998), three of moderate quality (Loreaux et al., 2015; Gray et al., 2011; de Boer et al., 2005) and seven of high quality (Reed-Knight et al., 2016; Engelmann et al., 2014; Gumidyala & Greenley, 2013; Mackner et al., 2012; Herzer et al., 2011a; Herzer et al., 2011b; van der Zaag-Loonen et al., 2004).

It is important that the findings of the systematic review are interpreted in light of the methodological strengths and weaknesses of included studies. Methodological strengths included the use of valid and reliable HRQoL measures across studies, the use of established instruments for measuring psychological factors in all but one study (van der Zaag-Loonen et al. 2004), the use of multivariate analyses (Reed-Knight et al., 2016; Loreaux et al., 2015; Engelmann et al., 2014; Mackner et al., 2012; Gray et al., 2011; Herzer et al., 2011a; Herzer et al., 2011b; de Boer et al., 2005; van der Zaag-Loonen et al., 2004) and clear reporting of aims and hypotheses and discussion of limitations across all studies. All of the studies used cross-sectional designs which can be viewed as a methodological weakness. To capture the causal influence of psychological factors on HRQoL, longitudinal designs are required, as both HRQoL and the influencing factors may change over time. For example, HRQoL may worsen over time for some adolescents but improve for others and these changes can coincide with changes in mood or anxiety (Tyack et al., 2016). Two studies had a participation rate below 50% which can introduce selection bias (Loreaux et al., 2015; de Boer et al., 2005). Six studies did not report information about non-responders and

measures undertaken to address non-responders (Jelenova et al, 2016; Loreaux et al., 2015; Gray et al., 2011; Herzer et al., 2011a; Herzer et al., 2011b; de Boer et al., 2005). This hinders the readers assessment of potential sampling bias. The two studies with a low overall quality rating failed to control for important confounding variables like disease activity (Jelenova et al, 2016; MacPhee et al, 1998).

**Table 2.** Risk of bias and quality ratings for included studies

Theme	First Author	Quality of reporting	Risk of Selection bias	Risk of Information bias	Risk of Confounding	Overall quality
Psychological Morbidity	Reed-Knight (2016)	High	Low	Low	Low	High
	Loreaux (2015)	High	Moderate	Low	Low	Moderate
	Engelmann (2014)	High	Low	Low	Low	High
	Gumidyala (2013)	High	Low	Low	Low	High
	Mackner (2012)	High	Low	Low	Low	High
	Gray (2011)	Moderate	Moderate	Low	Low	Moderate
	Herzer (2011b)	High	Low	Low	Low	High
Self-Concept	De Boer (2005)	Moderate	Moderate	Low	Low	Moderate
Stress & Coping	Gumidyala (2013)	High	Low	Low	Low	High
	Herzer (2011)	High	Low	Low	Low	High
	Herzer (2011a)	High	Low	Low	Low	High
	Van der Zaag-Loonen (2004)	High	Low	Low	Low	High
	Mac Phee (1998)	High	Low	Low	High	Low
Parenting Style	Jelenova (2016)	Moderate	Moderate	Low	High	Low

■ High 
 ■ Moderate 
 ■ Low

## Psychological Factors associated with HRQoL

Twelve different psychological factors were identified, which were categorised into four broader categories: psychological morbidity, self-concept, stress and coping and parenting style. An overview of the psychological factors and results for each category are shown in Table 3.



**Table 3.** Summary of included studies by psychological factor

Category		Psychological Factor	Study	Conclusions
Psychological Morbidity	Adolescent	Internalising symptoms - anxiety depression and somatisation  Depressive symptoms  Psychiatric disorders - anxiety, depressive, adjustment disorders  Externalising symptoms - delinquent and aggressive behaviours	Reed-Knight et al., Mackner et al.*, Gray et al.  Loreaux et al., Herzer et al. (2011b)  Engelmann et al.  Mackner et al.*, Gray et al.	Adolescent psychological morbidity was consistently significantly associated with poorer overall HRQoL.          Both studies reported a significant negative association between parent depressive symptoms and HRQoL
	Caregiver	Depressive symptoms	Reed-Knight et al., Loreaux et al.	
Self-Concept	Adolescent	Self-esteem Self-perception	De Boer et al.	Overall sense of self-esteem was a significant predictor of HRQoL.
Stress & Coping	Adolescent	Coping strategies	Van der Zaag-Loonen et al., MacPhee et al.**	Inconsistent evidence was found for the association between adolescent coping and HRQoL.
	Caregiver	Coping strategies Illness-related parenting stress	MacPhee et al.** Herzer (2011b)	Caregiver's use of negative coping strategies, parental stress and clinically elevated difficulties in family functioning were found to be significantly associated with reduced HRQoL.
	Family	Family-functioning	Gumidyala & Greenley, Herzer et al. (2011a)	
Parenting Style	Caregiver	Child-reported parent behaviour	Jelenova et al.	Positive parental behaviours were significantly positively correlated with HRQoL and negative parental behaviours significantly negatively correlated with HRQoL.

\* only looked at school functioning \*\* only looked at satisfaction with health status

### ***Adolescent Psychological Morbidity***

Seven studies examined the relationship between adolescent psychological morbidity and HRQoL (Reed-Knight et al., 2016; Loreaux et al., 2015; Engelmann et al., 2014; Gumidyala & Greenley, 2013; Mackner et al., 2012; Gray et al., 2011; Herzer et al., 2011b). Four of those studies measured internalising symptoms (Reed-Knight et al., 2016; Gumidyala & Greenley, 2013; Mackner et al., 2012; Gray et al., 2011), two studies depressive symptoms (Loreaux et al., 2015; Herzer et al., 2011b), one study psychiatric disorders (Engelmann et al., 2014) and two studies externalising symptoms (Mackner et al., 2012; Gray et al., 2011). The findings from the seventh study had to be disregarded because internalising symptoms were integrated into a broader individual risk index (Gumidyala & Greenley, 2013). Adolescent psychological morbidity was consistently associated with poorer overall HRQoL. Two studies demonstrated that this association persisted after statistically controlling for disease activity (Loreaux et al., 2015; Herzer et al., 2011b).

### ***Caregiver Psychological Morbidity***

Two studies (Reed-Knight et al., 2016; Loreaux et al., 2015) reported a significant negative association between parent depressive symptoms and HRQoL. Loreaux et al. (2015) demonstrated that the significant association persisted after statistically controlling for disease activity. They also found that parent depression significantly moderated the relationship between adolescents' depressive symptoms and HRQoL, but only among parents who reported higher depressive symptoms.

### ***Self-Concept***

De Boer et al. (2005) demonstrated that self-esteem was a significant predictor of HRQoL. Positive correlations were found between self-esteem and all of the domains of HRQoL, but the direction of causality could not be deduced from the results. The study further found that the self-esteem of adolescents with IBD did not differ from their healthy peers. However, disease activity which may have the potential to impact adolescents' self-concept was not measured by the study. De Boer et al. (2005) also reported positive association between several self-perception subscales like social competence, close friendships, athletic competence, physical appearance and various domains of HRQoL.

### ***Adolescent Coping***

Two studies investigated the relationship between adolescent coping and HRQoL, with mixed results. MacPhee et al. (1998) reported no significant association between coping and adolescents quality-of-life health scores whereas van der Zaag-Loonen et al. (2004) found significant associations between specific coping styles and certain domains of HRQoL. For example, adolescents who used passive coping behaviours reported poorer HRQoL and those who were optimistic about the course of their illness and attributed power to medical caregivers reported better HRQoL. Van der Zaag-Loonen (2004) provided more differentiated results considering generic and disease-specific coping styles and their association with all HRQoL domains of the IMPACT-II (NL). MacPhee et al. (1998), on the other hand, clustered different coping patterns into adaptive and maladaptive categories. They further used a generic quality of life measure and focussed solely on the satisfaction with health status domain; this limits the conclusions that can be drawn about general HRQoL.

### ***Parental Stress and Coping***

Herzer et al. (2011b) reported that increased parent stress was significantly associated with reduced HRQoL in all but one domain (body image). MacPhee et al. (1998) found a significant negative correlation between parental coping styles and quality-of-life health scores. Given that the results are based on measuring satisfaction with health status rather than general HRQoL, it would be prudent to interpret these results with caution. Also, no assumptions about the direction of causality could be made. The authors suggested that parents used more strategies to integrate family members, enhance family support and seek information from health professionals when adolescents reported lower health satisfaction scores.

### ***Family Functioning***

Two studies examined the link between family functioning and HRQoL (Gumidyala & Greenley, 2013; Herzer et al., 2011a). Herzer et al. (2011a) found that clinically elevated difficulties in particular domains of family functioning like problem-solving, communication and general family functioning had a significant negative impact on HRQoL in several domains (general wellbeing, social functioning). This negative association persisted after controlling for disease activity and type of IBD. Gumidyala & Greenley (2013) who examined the association between HRQoL and three different risk domains, reported that contextual variables comprising of family functioning and socioeconomic status were most consistently associated with HRQoL.

### ***Parenting Style***

Jelenova et al. (2016) reported that positive parental behaviours were significantly correlated with better adolescent-reported HRQoL and hostile and

inconsistent parental behaviours with reduced adolescent-reported HRQoL. However, on the parent-reported HRQoL measure, these associations were only significant for fathers, but not for mothers.

## **DISCUSSION**

To the author's knowledge, this is the first systematic review that examined and synthesised psychological factors associated with HRQoL in adolescents with IBD. Research indicates that the symptoms and treatment of IBD as well as the chronic, relapsing and remitting course of the illness, can interfere with and limit adolescents' psychosocial and school functioning (Mackner et al., 2013). Pain and fatigue can result in work or school absences, dietary requirements and the need to maintain close proximity to toilets can cause restrictions in social activities and the unpredictable nature of IBD can make it difficult to plan ahead (Devlen et al. 2014). HRQOL is an important patient-reported outcome measure that attempts to assess the holistic effects of IBD. Better knowledge of psychological factors that impede HRQoL may promote the consideration of psychological issues in overall treatment planning and guide clinical interventions.

Adolescent psychological morbidities including depression, anxiety, somatisation and the use of passive coping behaviours were consistently found to be associated with reduced HRQoL. A study by Jones et al. (2006) found that adult IBD patients were significantly more likely to endorse escape-avoidance coping strategies as compared to healthy peers and relied significantly less on planful problem solving and positive reappraisal. Research further indicates that the prevalence of psychopathology, especially anxiety and mood disorders, may be higher in

paediatric IBD patients than in healthy peers (Szigethy et al., 2010; Mackner et al., 2006). A randomised controlled study by Szigethy et al. (2014) demonstrated that psychological therapies not only reduced depression severity in adolescents with comorbid IBD and depression but also improved adolescents' HRQoL at 3 months. These findings suggest that adolescent psychological morbidity may be a factor that merits consideration in clinical decision making and treatment planning for adolescents with IBD.

Adolescents' self-esteem and certain subscales of self-perception were also significantly associated with reduced HRQoL, but de Boer et al. (2005) were unable to make any assumptions about the direction of causality. They acknowledged the possibility that better HRQoL helps to improve adolescents' self-concept. A meta-analysis did not indicate that adolescents with IBD report significantly lower levels of self-esteem than healthy peers (Pinquart, 2013). However, Sajadinejad et al. (2012) reported that faecal incontinence and lack of bowel control can cause stigmatization and result in reduced self-worth in adult IBD patients. A qualitative study by Pihl-Lesnovska et al. (2010) found that being very thin due to illness-related weight loss or rapid weight associated with corticosteroid treatment affected the self-image of patients with Crohn's disease. Casati and Toner (2000) explained that body image can be a concern for individuals with IBD as medication and surgery can significantly change their appearance.

Further associations were found between reduced HRQoL and caregiver depressive symptoms, parental stress, clinically elevated difficulties in family functioning and caregiver's use of negative coping strategies and parenting behaviours. The

use of positive caregiver coping styles and parenting strategies was associated with better HRQoL. Research indicates that paediatric IBD can also impact on parental and overall family functioning. Increased levels of psychopathological symptoms and a high life-time prevalence of depression were found in mothers of children with IBD (Engstrom, 1991; Burke et al., 1994). Herzer et al. (2011a) reported that a high percentage of families of adolescents with IBD endorsed clinically elevated difficulties with family functioning. Loreaux et al. (2014) identified parental depression as a moderator of the relationship between adolescent depression and HRQoL. The above findings suggest the importance of considering parental and family functioning in overall treatment planning for paediatric IBD patients. Clinicians could consider the monitoring of parent and family functioning during clinic visits to identify adolescents who may be at increased risk of impaired HRQoL. Where appropriate, a referral for psychological interventions could be considered for caregivers or families (Herzer et al., 2011a). Wysocki et al. (2008) found that behavioural family systems therapy that targeted and enhanced family communication and problem-solving in families of adolescents with diabetes resulted in improvements in clinical diabetes outcomes and diabetes-related family conflicts.

The findings of this systematic review have to be considered in light of the methodological weaknesses of the included studies. It is a common view that cross-sectional studies do not allow for the inference of temporal causal relations (Mann, 2003). It also has to be noted that the majority of studies had samples with predominantly no or mild disease activity. However, disease activity was frequently associated with the HRQoL of adolescents with IBD and not all studies adjusted for this potential confounder. This may impact on the generalisability of

findings to the entire population of adolescents with IBD, particularly those with moderate or severe disease activity.

## **Implications for Future Research**

The findings of the systemic review indicate the merit of further exploration of psychological factors associated with HRQoL. Future research may try to replicate the findings of the included studies as certain psychological factors were examined only in single studies. Studies that examine a combination of psychological, social and clinical factors and their respective influence on HRQoL may be valuable to clarify the most pertinent associations. Longitudinal studies could capture changes in psychological factors and HRQoL over time and thus, advance the understanding of temporal relationships between the two variables. Future research may further focus on assessing the outcomes of interventions that target psychological determinants of HRQoL or investigate the effect of medical treatment versus multi-disciplinary approaches on the HRQoL of adolescents with IBD.

## **Limitations**

The exclusion of unpublished studies may have resulted in publication bias which could be regarded as a limitation. However, peer-review also acts as a filter to ensure that only high-quality research is published and only including peer-reviewed articles offers reassurance about the quality of included articles (Kelly et al., 2014). The review exclusively focussed on studies that examined psychological factors. While beyond the scope of this review, the inclusion of clinical, social and treatment-related factors may have added to a broader understanding of the determinants of HRQoL and the interrelationships between these determinants. Other limitations that have



been acknowledged relate to the methodological weaknesses of the included studies such as the exclusive use of cross-sectional designs, insufficient control of confounding factors and low response rates.

## **CONCLUSIONS**

Adolescents with IBD have poorer health related-quality of life than healthy peers. Awareness of factors that may result in impaired HRQoL can aid the identification of at-risk adolescents and multidisciplinary treatment planning. A number of modifiable psychological factors that influence the HRQoL of adolescents with IBD have been identified. Clinicians may want to consider screening for these factors and where appropriate, offer preventative and therapeutic interventions. However, future research may be required to (1) establish the temporal relationships between psychological factors and HRQoL, (2) replicate findings based on single studies, and (3) assess whether psychological interventions effectively improve HRQoL outcomes.

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Institute of Health  
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## **CHAPTER TWO MAJOR RESEARCH PROJECT**

**“I guess it’s just the fear of the unknown”: An Interpretative  
Phenomenological Analysis of the experiences of IBD patients  
transitioning from paediatric to adult care**

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## Plain English Summary

**Background:** Eventually, all young people with Inflammatory Bowel Disease have to move from Children's to adult hospital. The changes associated with this transition can be challenging for young people. They have to move to a new hospital, new health professionals, and have to become more independent from their parents. However, fairly little is known about young people's experiences and needs as they pass through this process. Research that explores their perspectives could improve health professionals' understanding of their needs and how to best support them.

**Aims:** This study aimed to better understand how adolescents experience the move from Children's to adult hospital, what their needs are and what they think about the process.

**Methods:** Interviews were carried out with seven young people who were moving or had completed the transition out of Children's hospital. The semi-structured interviews were audio recorded, typed out word-for-word and analysed using Interpretative Phenomenological Analysis.

**Results:** Young people felt nervous about meeting new medical staff, attending appointments without parents and about becoming more independent, but also a bit excited. A number of things were experienced as helpful: being well-informed; the transfer happening

over time; there were face-to-face handover meetings and they had the chance to practice attending appointments alone.

**Conclusions:** The study provided important insights into young people's experiences and could inform the improvement of transition practices that meet young people's needs.

## ABSTRACT

*Background:* Transition is increasingly recognised as an important aspect of healthcare provision. However, fairly little is known about the experiences and needs of Inflammatory Bowel Disease (IBD) patients as they pass through this process. This study aimed to explore the transition experiences and needs of adolescents with IBD, and their views on transitional care provision.

*Methods:* Semi-structured interviews were conducted with seven adolescents with IBD who were in the process of transitioning or had completed transition from paediatric to adult care. Transcripts were analysed using Interpretative Phenomenological Analysis.

*Results:* Two main themes were identified: (1) Moving from the Known to the Unknown with subthemes of uncertainty and mixed emotions, the importance of information and support, losing familiar relationships, overlap in care provision and timing of transition (2) A Less Coddled Approach with subthemes of transfer in responsibility and differences between paediatric and adult care.

*Conclusions:* Adolescents experience a range of challenges and emotions in response to the multifaceted relational and systemic changes associated with healthcare transition. They like to be well informed about transition plans and adult care providers, value a gradual and structured transition process and benefit from opportunities to develop self-management skills. Joint appointments provide reassurance and build a bridge between paediatric and adult care.

## INTRODUCTION

Inflammatory Bowel Disease (IBD) has a peak incidence during adolescence with approximately 25% of patients presenting before the age of 20 (Kelsen & Baldassano, 2008). Eventually, paediatric patients have to move from child to adult health services, and hence transition has become an increasingly important clinical issue. Transition is defined as “the purposeful planned movement of adolescents with chronic diseases from child to adult-oriented care” (Blum et al., 1993, p. 570). A successful transition process should ensure the provision of uninterrupted, coordinated and developmentally appropriate healthcare and promote adolescents’ engagement with adult services (Paone et al., 2006; Baldassano et al., 2002; Blum et al., 1993).

The changes associated with transition can be challenging for young people. Adolescents are expected to become more responsible for managing their healthcare as they move from paediatric to adult-oriented care cultures. While paediatric services are family-focussed with significant parental involvement, adult services expect greater autonomy and self-management (Cole et al., 2015; Leung et al., 2011; Hait et al., 2009). Healthcare transition further coincides with other physical and psychosocial transitions like completing high school, entering higher education or employment, disengaging from parental control and increasing self-governance (Afzali & Wahbeh, 2017; Bollegala & Nguyen, 2015, Baltes & Silverberg, 1994). These overlapping events can pose a number of risks for adolescents with chronic diseases including disengagement from medical services, poor clinic attendance, non-adherence to medication and increased healthcare utilisation (Goodhand et al., 2010; Van Wallegghem et al., 2008; Gurvitz et al., 2007). Transition guidelines recommend the use of structured transition

programmes to prepare adolescents for new responsibilities, to facilitate their engagement with adult services and to improve their drug compliance and clinic attendance (Brooks et al., 2016; West of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network (WoSPGHaN), 2014). However, existing transition programmes for IBD patients are highly variable and in the absence of strong evidence, no ideal transition model has been identified (Azfali & Wahbeh, 2017; Brooks et al., 2017; Leung et al., 2011).

There is a strong political drive to tap into the real-life experiences of service users and involve them in the planning and development of health services (The Scottish Government, 2007). IBD-specific transition guidelines also suggest that adolescents' concerns and perspectives should be considered (Brooks et al., 2017; Leung et al., 2011). However, IBD transition research has predominantly focussed on the perspectives of health professionals (Strohl et al., 2017; Paine et al., 2014; Wright et al., 2014; Sebastian et al., 2012; Hait et al., 2009). The perspectives of IBD patients have remained largely unexplored and hence, fairly little is known about their experiences and transitional care needs. Two patient survey studies identified starting over with a new doctor and lack of communication and understanding of IBD as primary barriers to successful transition (Herzer Maddux et al., 2017; Bennett et al., 2016). Patients further indicated that it was important for them to receive a structured transition plan and information, for example about self-management skills and the differences between paediatric and adult care. A qualitative study by Gray et al. (2015) highlighted that adolescent IBD patients in the United States felt inadequately informed about the transition process and had negative expectations about the quality of care in adult services. Adolescents further expressed a desire to build autonomy prior to transition and a preference for a flexible timing of transition.

Transition is increasingly recognised as an important aspect of healthcare provision. However, gaps remain in the understanding of IBD patients' perspectives and needs during this process. To date, no UK based study has exclusively investigated the opinions of adolescents with IBD themselves. Research that gives adolescents an opportunity to discuss their perspectives, could improve the understanding of their transitional care needs. This study therefore aimed to explore the transition experiences and needs of IBD patients, and their views on transitional care provision. A qualitative methodology was deemed appropriate because it gives a voice to young people and allows them to express their personal experiences and concerns (Larkin et al., 2006).

## **METHODS**

### **Study Design**

The study followed the qualitative methodology of Interpretative Phenomenological Analysis (IPA). IPA is underpinned by phenomenology, hermeneutics and ideography. This means that it focuses on gaining a detailed understanding of a particular experiential experience and the meaning attached to it by participants through the researcher's systematic interpretation of their individual accounts (Smith et al., 2009).

### **Procedure**

Ethical approval was granted by the North West - Preston Research Ethics Committee and NHS Greater Glasgow & Clyde Research and Development (Appendix 6, p.73). Recruitment took place between October 2017 and February 2018. A total of 79 potential participants were identified by the adult

gastroenterology service at Queen Elizabeth University Hospital and sent a research pack (Appendix 7, p.79). Those interested were asked to return a response form to the researcher. The researcher then contacted the person to answer any questions and arrange an interview. The researcher did not have access to participant information prior to receiving their response form. To increase the response rate, a reminder letter with another research pack was sent out six weeks after posting initial invitations (Appendix 8, p.86).

Semi-structured interviews were conducted in a private clinic room. Written informed consent was sought from all participants prior to commencing interviews (Appendix 9, p.87). The majority of interviews lasted for around 60 minutes. An interview guide was devised through the review of relevant literature and the feedback from health care professionals (Appendix 10, p.89). It was used as a loose guide, in a flexible manner to allow participants to direct the interview and modified dynamically following on from participant interviews. Prompts and follow-up questions were used to gain a deeper understanding of participants' experiences and their interpretations. All interviews were audio-recorded and transcribed verbatim prior to analysis. Identifying information were removed and gender appropriate pseudonyms assigned to preserve confidentiality and anonymity.

## **Data Analysis**

Data analysis was conducted in line with the principles of IPA (Smith et al., 2009). The researcher initially read and re-read transcripts to increase familiarity with the text and noted descriptive, linguistic and conceptual comments. Emergent themes were then developed and clustered together to form superordinate

themes and sub-themes. Each transcript was separately analysed in this stepwise manner before looking for themes across all seven transcripts (Smith et al., 2009). An example of the coding process is provided in Appendix 11, p.93.

Three transcripts were independently analysed by two research supervisors to increase the consistency and coherence of the analysis, and to ensure that the analysis was not confined to one perspective (Yardley, 2015). Themes identified by the researcher were also discussed in research meetings to further verify the validity of the analysis.

## **Reflexivity**

The interpretation process which is an integral part of IPA methodology must take into account the researcher's prior experiences, assumptions and preconceptions. The researcher needs to remain self-questioning and reflect on the influence of their background and how it shapes the nature of the IPA interview and the interpretative process (Smith et al., 2009).

The researcher had no experience of working with young people with IBD. However, she had carefully reviewed the relevant literature and spoken to clinicians in this field which provided some insight into the challenges faced by participants. As a Trainee Clinical Psychologist, with Cognitive Behavioural Therapy training the researcher was aware of the range of emotional, cognitive and behavioural responses healthcare transition may evoke in young people. Her knowledge of child development may have shaped the interpretation of data; the researcher tried to make sense of young people's transition experiences in terms of their cognitive, emotional and social development. The researcher's inclination to use a biopsychosocial framework for understanding individual's experiences has



likely influenced the interview process and subsequent data analysis. Reflexivity was promoted throughout the research process through regular discussion with supervisors who had experience with IPA research.

## RESULTS

Participants were English speaking adolescents aged 16 years and above with an established diagnosis of IBD who completed transition within the past 24 months or were in the process of transitioning. Adolescents with a diagnosis of a learning disability were excluded. Seven participants were recruited. This is within the sample size recommendations for professional doctorate IPA research (Smith et al., 2009; Smith & Osborne, 2003). Given the idiographic focus in IPA, studies usually benefit from small sample sizes. The concentrated focus on a small number of cases allows an in-depth analysis of individual experience which in IPA is preferable to a broader, superficial and simply descriptive analysis of numerous individuals (Hefferon & Gil-Rodriguez, 2011; Smith et al., 2009). Participants were aged between 16 and 18 years old. Four participants were female, three participants were male. Table 1 provides a summary of the characteristics of the participants.

**Table 1.** Summary of participant characteristics

	Participant						
	Sara	Amy	Max	Liam	Zoe	Tim	Eva
<b>Age</b>	18	17	17	16	17	16	18
<b>Diagnosis</b>	Crohn's Disease	Crohn's Disease	Crohn's Disease	Ulcerative colitis	Crohn's Disease	Crohn's Disease	Crohn's Disease
<b>Age of onset</b>	12 years	14 or 15 years*	13 years	11 years	15 years	13 years	6 years
<b>Transition status</b>	Transition completed	Transition ongoing	Transition completed	Transition ongoing	Transition ongoing	Transition ongoing	Transition completed

\*participant was unable to recall the exact age of onset

Participants openly talked about their experiences of living with IBD and the challenges they have faced since their diagnosis. Some participants like Zoe described losses that were associated with their illness:

*“I had to stop gymnastics back then at the time, so that was something that I was quite upset about. (...) I was not allowed to do any physical activity because I wasn't allowed to lose any weight. (Zoe, )*

The majority described periods of disease activity and remission. It was apparent that during periods of disease activity IBD symptoms and treatments have impacted participants' social lives, school functioning, and emotional wellbeing:

*“I didn't have any energy to like make any friends and things. I was putting all this effort into just being at school (...) It really kind of really took away from the sociable aspect of life.” (Sara, 2.42)*

*“I did sometimes miss out on things which wasn't great like. (...) all my friends were doing stuff after school and having a big sleepover and I couldn't go until later because my drinks ca only be made up for 24 hours.” (Eva, )*

*“Well it's pretty hard to focus on school work, so it was a bit unsettling, it was dead scary. Very hard for me to bounce back as well as I've done anyway.” (Liam, )*

*“I was off quite a lot. Sore stomachs in school as well and yeah, I was off quite a good bit.” (Tim, )*

Remission was achieved and maintained through medication, life style changes and for one participant surgery. During remission IBD can reportedly be “really manageable” (Amy,) and a number of participants explained that it “doesn’t affect me anymore” (Max, ). Others, like Zoe see an improvement in their condition, but are still regularly affected by their IBD symptoms:

*“It’s more the tiredness that affects me now, like I get really tired; especially at night like I always feel like I need my bed after I’ve been at school” (Zoe, )*

Participants also appeared motivated to discuss their transition experiences. They reflected on the positive, as well as the challenging aspects of their experiences and considered how the transitional care for IBD patients could be improved.

Two superordinate themes emerged from the participants’ account: *Moving from the Known to the Unknown* and *“A Less Coddled Approach”* (Eva, 12.16). Table 2 details the emergent themes.

**Table 2.** Superordinate and subordinate themes

Superordinate theme	Sub-themes
Moving from the Known to the Unknown	<i>Uncertainty and mixed emotions</i> <i>The importance of information and support</i> <i>Losing familiar relationships</i> <i>Overlap in care provision</i> <i>Timing of transition</i>
<i>“A Less Coddled Approach”</i>	<i>Transfer of responsibility</i> <i>Differences between paediatric and adult care</i>

## Theme 1: Moving from the Known to the Unknown

This theme emerged from participants' personal stories of transitioning from the Children's to adult hospitals. It consists of five subthemes: *uncertainty and mixed emotions, the importance of information and support, losing familiar relationships, overlap in care provision and timing of transition.*

### Uncertainty and Mixed Emotions - *"...it was going to be a big change" (Max)*

Most participants highlighted that the move to adult hospital is associated with a great deal of change and uncertainty. Adolescents commonly spent several years in Children's hospital and felt comfortable with the familiar paediatric professionals, environment and clinic routines. The prospect of change was experienced as daunting by the majority of participants, especially in the early stages of the process.

*...“when I was told that we were going to start transitioning I was a wee bit wary” (Amy, 5.27).*

Participants clearly valued the friendly and familial atmosphere in Children's hospital and wondered about the differences that they were likely to face in adult services. Many participants had quite negative expectations like they *“may not have the same care”* (Max 7.32), *“they weren't gonna support me as much as the Children's hospital”* (Amy, 6.42) or it will be *“completely anonymous”* (Eva, 12.8). A couple of participants felt anxious because adult hospitals unlike Children's hospital did not routinely perform endoscopies and colonoscopies under sedation. Only one participant felt mostly unconcerned about the transition: *“I don't really*

*know what I would be stressed about”* (Tim, 8.24) and a few others described excitement about becoming more mature and independent. Some participants like Liam also experienced mixed emotions:

*“I want to get it out of the way, just get it done. But I’m still just thinking to myself, hold on, maybe I’m not quite ready yet.”* (Liam, 8.26)

There can also be a shift of adolescents’ emotions over the course of the transition process. Many participants acknowledged that they became gradually more acceptant about moving to adult hospitals. It seemed like the gradual, structured nature of the transition and learning about the process supported this emotional change:

*“...they really kind of eased me into the idea and then they kind of started to tell me about it and tell me what it would be like”* (Sara, 5.23)

*“it was good because I just eased into it... got like time to learn what the new hospital is like, what’s the differences in that”* (Max, 12.22)

#### **Overlap in Care Provision - “... a proper bridge over to adult hospital” (Amy)**

All participants were offered two joint paediatric and adult transition appointments; one at the Children’s Hospital and the other at adult hospitals. These appointments were experienced as helpful by the majority of participants, for a number of reasons. Many emphasised that the first joint clinic alleviated

some of their initial anxiety and apprehension about meeting unfamiliar adult professionals:

*“... having the people that I’ve known for years now would really be comforting, I think maybe if it was just me and the new doctor I’d maybe feel a bit intimidated.”* (Liam, 9.1)

The transition meeting at the adult hospitals further allowed adolescents to familiarise themselves with the unknown adult hospital environment. Sara experienced it as helpful to have familiar paediatric professionals present during this first visit: *“it was even just nice to turn up... and see a friendly face that I knew from the other hospital”* (Sara, 10.18). A few others like Amy felt reassured by the continuity in care that was provided through the overlap in paediatric and adult care provision:

*“That they are actually in communication with each other. That they’re not just like oh here is a file this is who you are going to take on, now that they are 16...Yeah, I have a lot more confidence in that I won’t get lost in a system somewhere.”* (Amy, 7.43)

Participants, however, had differing views about the size of the joint meetings. While Sara perceived the presence of the large number of professionals as supportive others like Tim and Zoe, experienced it as somewhat overwhelming:

*“I just felt it was a bit like a hearing, there were just four people all around me and you know it just felt a bit, uh overwhelmed”* (Tim, 6.8).

*“... it was just like telling all six of them, it would probably have been better if it was maybe like one to one or like two on one.”*  
(Zoe, 7.39)

In contrast to the other participants, Tim generally deemed the joint appointments as *“a bit of a waste of time”* because he *“didn’t really have much to say”* and *“didn’t really have any questions either”* (Tim, 11.12; 7.4).

### **The Importance of Information and Support - *“...better to know a bit more about it”* (Zoe)**

The importance of receiving sufficient information about the transition process, adult services and the new medical team was discussed by most participants. It was evident that being well-informed can reduce the uncertainty adolescents experience at the time of transition:

*“We were almost given a brief summary of what will happen in the transition and it did seem (pause) very good, very helpful like going to different things that will that will help me understand the transition a lot more ... knowing what will happen”* (Liam, 13.22)

However, some participants indicated that they can struggle to remember information that was discussed at appointments. Tim appeared surprised about the format of the transition clinics; he said he was not *“really expecting it to be honest”* and was not sure if he *“knew about it”* (Tim, 6.21;27). Zoe forgot the names of adult professionals after the transition meeting: *“Well, they did introduce themselves, but I’m very forgetful”* (Zoe, 13.13). The issue of correctly

understanding and recalling important decisions and specific information may be of increasing significance as adolescent IBD patients move to adult services and become more independent from their parents. One participant suggested that the provision of written information would have been helpful.

A few participants referred to the need to feel supported during transition. Quite divergent perspectives existed with regards to the adequacy of support they received. Some participants like Sara, felt well prepared and satisfied with the support that was provided: *“I was very impressed actually with the way that they helped me transition, because there was huge bit of, you know, support for you”* (Sara, 6.40). Eva, on the other hand thought that although she had *“always had really great support and care, in terms of transitioning it was quite rough and there could definitely be more done to help you out there”* (Eva, 15.44). She suggested that adolescents could, for example, benefit from connecting with other young IBD patients through a support group. Max talked about meeting other adolescents with IBD at an event organised by the Children’s hospital and described this experience as useful.

#### **Losing Familiar Relationships - *“...getting to know each other and that”* (Max)**

Most participants described longstanding, close relationships with paediatric health professionals and felt reluctant to let go of this familiarity with their medical team. They also expressed apprehension about transferring to a new medical team:

*“I don’t really want to move because I like it here so much (laughs)*

*... like I was comfortable, I knew everyone”* (Sara, 5.23)



Many participants voiced concerns about starting over with adult professionals. One participant felt nervous because he did not know what to expect during consultations, *“what questions he’ll [doctor] ask, what answers he’ll be expecting”* (Liam, 12.37). Some appeared worried about the mutual unfamiliarity in relationships with adult professionals. They highlighted professionals’ lack of knowledge about their medical history as a potential disadvantage or described feelings of discomfort about discussing health problems with an unfamiliar professional. This discomfort may be exacerbated for adolescents with IBD due to the nature of their symptoms:

*“It’s kind of like a taboo I think a lot of the time, like you don’t really tell people, because it can be embarrassing. I think that with other (...) conditions it’s less embarrassing, you can talk about it more whereas people don’t really want to know when it involves like having to go to the bathroom all the time and that kind of thing.”* (Eva. P:2 L:10)

However, participants also appeared hopeful and some expressed confidence that they will gradually build relationships with their new adult medical team.

*“... we knew them [paediatric professionals] quite well, but I think we’ll get to know the adult people as well.”* (Tim, 8.39)

### Timing of Transition - *“... cause obviously, I was turning 16” (Liam)*

Chronological age was the primary reason for initiating transition to adult hospitals. All of the participants said transition was first mentioned when they were 16 years old. Participants also thought that the timing of transition was dependant on disease stability and readiness to move to adult care. It was not entirely clear how readiness was assessed by the paediatric team, but one young person thought that *“they could judge it professionally that I was um ready to move”* (Sara, 11. 2) and another remembered that professionals *“would give you checklists on how comfortable you are with this”* (Eva, 8.41).

With regards to participants’ perspectives on the best time for transition, several participants emphasised that transitioning at a time of disease stability is preferable:

*“if I was undergoing a bad spell or something maybe it would be a lot tougher”* (Tim, 9.24).

A few participants also thought that life circumstances should be taken into account. They highlighted that transition can add to adolescents’ stress if it coincides with other challenging life events like a loss or high-school exams:

*“So, I feel like that’s more pressure on me (pause) ... more weight on my shoulders really. ... It feels like there is another thing at the back of my head... I always think about the transition... so it almost adds to kind of stress levels.”* (Liam, 11.4 &18)

## Theme 2: “A Less Coddled Approach”

All participants discussed the need to grow more independent from parents and assume a more active role in their healthcare. The three young people who had completed their transition contrasted their experiences in paediatric and adult services. This theme consists of two subthemes: *transfer of responsibility and differences between paediatric and adult care*.

**Transfer of responsibility - “... *it’s not right that my mum comes in as well*” (Sara)**

It was evident from all participants’ accounts that paediatric service delivery is family-focussed, and that parents are highly involved in adolescents’ medical care.

*“... for children’s services it’s very much like it’s you and your parent”*  
(Sara, 7.33).

*“I look up to my mum and she’ll, she’ll almost answer for me.”* (Liam, 16.2 & 8.44).

All of the participants associated the move to adult care with a transfer in responsibility from parents to the adolescent patient and discussed the need to adopt a more autonomous and active role in their healthcare. This involved attending appointments without parents and becoming responsible for correspondence with medical services.

*“You can’t as an adult go in with your parents... Adults are expected to be able to cope with it more and they are kind of left to their own devices more” (Amy, 7.23; 8.9).*

*“... at the adult hospital they don’t try and squeeze information out of you...You’ve got to just say it.” (Eva, 12.15)*

Participants described differing and ambivalent feelings about this change. A couple of participants like Zoe felt confident about attending appointments alone: *“that’s not really something that bothers me because I don’t mind just talking to other people by myself” (Zoe, 12.12)*. Others appeared keen and excited about growing more independent from their parents. However, some participants also felt nervous and indicated that it may take time to adapt to this change:

*“...maybe I still maybe need, half an appointment on my own, and then half an appointment with someone there to help and then eventually I’ll be on my own all the time.” (Liam, 8.27)*

Several participants suggested that the shift towards-adult-oriented care also constitutes a significant change for parents and that they too feel nervous and need time to adjust to stepping back from their involvement in adolescents’ medical care.

A couple of participants implied that adolescents are in a transitional developmental period, *“not a child or an adult” (Eva, 7.40)* and may therefore need extra support in an adult-oriented healthcare environment:

*“as much as I’m like becoming an adult I’m still (pauses) a child in the same sense...I don’t wanna to be left on my own.” (Amy, 7.1)*

*“going from Children’s to adults just doesn’t really cover it enough” (Eva, 7.40).*

Several participants discussed the benefit of practicing new self-management skills prior to moving to adult hospitals and appreciated that the Children’s hospital offered opportunities to attend appointments without parents:

*“I can almost transfer what I’ve been learning in the Children to the adult” (Liam, 14.32).*

### **Differences between paediatric and adult care - “...there’s all sorts of wee things” (Eva)**

Participants transitioned from the Children’s hospital to a number of different adult services. All three participants who completed their transition discussed differences between paediatric and adult care delivery. They noted that appointments in adult hospitals were shorter and less frequent and that it was difficult to get emergency appointments. Max also observed that professionals in adult hospitals did not provide information to parents and generally *“just didn’t give me as much information”* (Max, 10.21). Overall, Sara and Max expressed more positive views about adult care provision than Eva and seemed more comfortable and settled in their adult services.

*“it’s very similar to being in children’s services” (Sara, 8.37).*

*“the care is still the same, they still care a lot” (Max, 11.1).*

Eva appeared frustrated and dissatisfied with the medical care she received in adult hospital. She discussed how lacking relational continuity had negatively impacted her care and had also made it difficult to establish mutual familiarity in the relationships with her adult medical team: *“I have to explain these symptoms for the first time every time I see someone ... you can't get to know anybody”* (Eva, 13.31). She had further experienced difficulties accessing the adult service during a disease flare-up:

*“I was really really unwell. I, was barely at school, I had prelims [exams] that I just couldn't study for. I was not functioning, I couldn't leave my bed. And they gave me an appointment for four (emphasised) months' time to even consider starting treatment which was just absurd to me.”* (Eva, 15.18)

As a result, Eva still experienced adult hospital as *“daunting”* and had not developed *“that feeling of settling in”* (Eva, 14.7). She thought it would have made a difference if *“maybe for the first year or two you saw the same person every time you had an appointment”* (Eva, 14.6).

## DISCUSSION

Participants experienced multifaceted relational and systemic changes during their transition from Children's to adult hospitals. They moved from familiar to unknown service settings and healthcare delivery models, transferred from well-

known to unfamiliar medical teams, had to become more independent from parents and were expected to assume greater responsibility for their healthcare. These findings are consistent with existing evidence (Gray et al., 2018, Bennett et al., 2016). A systematic review by Gray et al. (2018) found that common challenges experienced by patients with chronic illnesses including IBD patients, fell into the domains of relationships, beliefs and expectations, lack of knowledge and deficits in skills and efficacy.

The changes associated with transition bring instability and uncertainty. These may add to the pre-existing uncertainty associated with the chronic and unpredictable nature of IBD which has been shown to produce physical, psychological and social stress in IBD patients (Pihl-Lesnovska et al., 2010). Devlen et al. (2014) reported that adult IBD patients remained concerned about their illness even during times of remission and were unable to plan ahead not knowing how they will feel (Devlen et al., 2014). Participants described a mixture of emotions as they passed through the process of transition. These resonated with the emotions described in Fisher's (2012) model of transition. Apprehension and ambivalence were common initial responses, but adolescents also described a sense of excitement, and gradual acceptance. Similar emotional responses of fear and ambivalence were reported in existing research (Tuchman et al., 2008; Reiss & Gibson, 2002). It appears that healthcare transition is not just an external event for young people, but an internal process. A number of factors seemed to influence how this process was experienced. These included the availability of information, perceived levels of support, timing of transition, as well as adolescents' beliefs and expectations about the transition process and adult care, their locus of control and confidence in their self-management skills.

Participants clearly valued the gradual and structured nature of their transition which gave them time to adjust and prepare for the move to adult care. The provision of sufficient information about transition plans and adult services, opportunities to develop self-management skills and joint paediatric and adult appointments were identified as particularly helpful features of the transition process. These needs are largely in keeping with relevant transition guidelines and best practice recommendations (Brooks et al., 2016; NICE, 2016; WoSPGHaN, 2014; Paone et al., 2006). The findings suggest that a structured transition programme that considers and addresses these needs promotes the development of self-management skills and facilitates the provision of uninterrupted, coordinated care and the continued engagement with health providers (Baldassano et al., 2002; Blum et al., 1993). This is an important insight as research identified deficits in self-management skills as a potential barrier to successful transition and indicated that adolescents with chronic illnesses such as IBD are at an increased risk of disengaging from health services (Gray et al., 2018; Sebastian et al., 2012; Van Wallegghem et al., 2008).

The findings of this study further support the notion that transition continues after adolescents' transfer to adult care. Participants who had completed their move to adult hospitals identified clear differences between paediatric and adult care delivery that required ongoing adjustment. A few participants reflected that adolescents are not fully-grown adults and often require more support than adult patients. This view is supported by the literature concerning adolescent development which emphasises that cognitive and emotional growth continues until the mid-twenties (Siegel, 2013). Nguyen et al. (2016) found that it can be challenging, and sometimes unrealistic for transitioning adolescent patients to



navigate services independently and assume full responsibility for their healthcare. Healthcare providers may therefore need to adopt a more gradual approach and be prepared to invest more time into caring for adolescent patients, for example, offering additional time during consultations (Bollegala & Nguyen, 2015; Nguyen, 2016). It was apparent that building relationships with adult providers was important to participants and the findings suggest it may be beneficial to support this process by ensuring relational continuity following transfer to adult providers. This may be of particular importance for IBD patients. Results suggest that there may be a taboo surrounding the symptoms of this particular chronic illness and that adolescents may initially feel embarrassed or uncomfortable discussing their symptoms with unfamiliar adult health professionals. These findings are supported by a qualitative study by Devlen et al. (2014) which found that IBD patients reported they were extremely embarrassed by their IBD symptoms.

While some common themes emerged from adolescents' narratives, the research also indicates that transition experiences and transitional care needs are idiosyncratic. The social-ecological model of readiness for transition emphasises that adolescents can differ in knowledge, skills, developmental status, beliefs, expectations, psychosocial functioning and their surrounding systems (Schwartz et al., 2011). Person-centred assessments could be helpful to identify individual support needs and promote the development of individualised transition plans (Brooks et al., 2016; Schwartz et al., 2011).

## **Strength and Limitations**

A strength of this study was that participants were at different stages in their transition, which allowed a rich understanding of adolescents' lived experiences across the process. In keeping with IPA methodology, the sample was fairly homogenous. All participants had a diagnosis of IBD and all, but one participant had Crohn's disease. The sample was further relatively gender-balanced and included participants from a narrow age range who had experienced a similar transition process. The qualitative methodology and small sample size of the study allowed for an in-depth analysis of participants' subjective experiences. However, in accordance with IPA principles the findings of the study are restricted in their generalisability which is a limitation of this methodology. The sample further consisted of volunteers and there is a possibility that their characteristics differ from those who decided not to participate. For example, the voice of adolescents who were hospitalised or undergoing a flare-up may have been missed. A further limitation of qualitative research is the influence of subjectivity and potential interpretation bias. While measures were taken to promote reflexivity, mitigate bias and increase the validity of the analysis, a completely objective analysis of the data would never be achievable.

## **Clinical Implications**

The study illustrated positive transition practices and indicated potential areas for improvement. Participants appeared to value the gradual and structured nature of their transition to adult hospitals and highlighted elements of the transition process that were particularly beneficial. These included providing adequate information about transition plans and adult service providers,

opportunities to practice self-management skills like attending appointments independently and the joint clinics with paediatric and adult healthcare teams. Participants reported that remembering verbally presented information can be difficult. It was suggested that the provision of written information about transition plans and new adult service providers including details about joint clinics and names and contact details of adult professionals could be helpful. Systematic reviews indicate that the supplementary provision of written information is perceived as beneficial by patients and can improve their retention of information provided during clinical consultations (Watson & McKinstry, 2009; Johnson & Sandford, 2005). One participant thought it would be useful to set up peer support groups for young people with IBD. Two others highlighted the importance of considering life circumstances in the timing of transition. The idiosyncrasies found in participants' transition experiences suggests that adolescents may benefit from the assessment of individual transition needs and the development of person-centred transition plans. This approach is also recommended in existing UK guidelines on the transition of adolescents with chronic digestive diseases (Brooks et al., 2016; WoSPGHaN, 2014). The findings further suggest that the transition process extends into adult hospitals where adolescents may need ongoing support to adjust and adapt to new adult care practices. Participants clearly valued familiarity in their relationships with health professionals and were eager to build relationships with adult medical teams. Continuity in care following the move to adult hospitals may be advantageous to support this process.

## **Implications for Future Research**

Paediatric and adult health professionals and caregivers could be included in future studies about transition to facilitate cross-group comparisons and to ensure that the experiences of all key stakeholders are captured. Qualitative data could inform the development of tools for the measurement of young people's transition needs. Information from such measures could be used to create individualised transition plans. Adolescent patients may have additional support needs following transfer to adult services and future research is needed to substantiate this supposition. Longitudinal studies could promote a better understanding of young people's post-transition experiences and care needs, and their long-term transition outcomes.

## **CONCLUSIONS**

The study elicited adolescents' lived experiences and provided important insights into their transition experiences and needs. Adolescents experience a mixture of emotions in response to the multifaceted relational and systemic changes associated with healthcare transition. Initial apprehension, fear and ambivalence can merge with excitement about becoming more independent. The research shows that adolescents prefer to be well informed, they valued a gradual and structured transition process and benefited from opportunities to develop self-management skills. Joint appointments provided reassurance and helped build a bridge between paediatric and adult care. Individualised plans may help to accommodate adolescents' idiosyncratic needs during transition.

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## Appendices

### Appendix 1 Summary of Author Guidelines

## JOURNAL OF PEDIATRIC GASTROENTEROLOGY AND NUTRITION

### ABOUT THE JOURNAL

The *Journal of Pediatric Gastroenterology and Nutrition (JPGN)* provides a forum for original papers and reviews dealing with pediatric gastroenterology and nutrition, including normal and abnormal functions of the alimentary tract and its associated organs, including the salivary glands, pancreas, gallbladder, and liver. Particular emphasis is on development and its relation to infant and childhood nutrition.

### SCOPE

The *Journal of Pediatric Gastroenterology and Nutrition* publishes original articles, special reports, review articles, rapid communications, case reports, letters to the editor, short communications, and commentaries on all aspects of pediatric gastroenterology, hepatology, pancreatology, and nutrition.

The journal follows the International Committee of Medical Journal Editors' Uniform Requirements for Manuscripts Submitted to Biomedical Journals (URM). Manuscripts must be prepared in accordance with the URM (N Engl J Med 1997;336:309-15 and updated at <http://www.icmje.org/>). Manuscripts not prepared according to the Instructions to Authors will be returned to the author(s) without review.

### ARTICLE TYPES

**Original Articles:** Original articles are full-length reports of original research. Original articles are accepted based on their scientific relevance, the originality of the work, and the priority of the work for *JPGN* and its readership. Authors should aim for accuracy, clarity, and brevity. Long introductions, repetition of data among tables, figures, and the text, and unfocused discussions should be avoided.

Original research articles should be approximately 18 double-spaced, numbered pages, including the title page, references, figures, and tables. Failure to comply with length restrictions may result in a delay in the processing of your paper. The following length targets (up to 3000 words for the text including Introduction, Methods, Results and Discussion) are recommended for Original Articles:

- Structured Abstract: maximum of 250 words
- Introduction: 1 page (about 250 words)
- Methods: 2-3 pages (up to 750-1000 words)
- Results: 2-3 pages (up to 750-1000 words)
- Discussion: 3-5 pages (up to 1000 words)
- References: limited to those critical and relevant to the manuscript (not more than 50)
- Tables and Figures: 4 total (legends limited no more than 100 words each)

- Additional/supplemental content may be submitted as "Supplemental Digital Content (SDC)", which has no space limitation (see section on SDC below).

**Review Articles:** Review articles are usually solicited by the Editorial Board. However, unsolicited reviews of exceptional interest will also be considered. Authors should contact the Editors before submitting a review to determine whether the topic and contents are appropriate for JPGN. All proposed reviews will be approved based on a submitted list of author(s) and a brief outline for the proposed review. Reviews should be balanced and unbiased. Review articles undergo peer review. While we allow some flexibility for Review Articles, authors should aim to follow the same guidelines as the Original Articles above (exception being an Unstructured Abstract of no more than 250 words): text with no more than 3000 words; no more than 50 references permitted; no more than 4 Tables/Figures; SDC permitted). Authors submitting longer Review Articles must justify the length in the cover letter.

For Systematic reviews/Meta-analyses, please follow the guidelines listed above, but please include a structured abstract of no more than 250 words. A [Preferred Reporting Items for Systematic Reviews and Meta-Analyses \(PRISMA\) Checklist](#) should be included at the end of the manuscript. Alternatively, the [MOOSE checklist](#) should be applied for meta-analyses of observational studies.

A full list and index of reporting guidelines can be found at [www.equator-network.org/library/](http://www.equator-network.org/library/). All can be downloaded as Word documents that can then be included at the end of the manuscript.

## MANUSCRIPT PREPARATION

Manuscripts that do not adhere to the preceding guidelines and following instructions will be returned to the corresponding author for technical revision before undergoing peer review. Concise, clearly written articles are more likely to be accepted for publication in the *Journal of Pediatric Gastroenterology and Nutrition*. Authors whose first language is not English are STRONGLY encouraged to ask a native English-speaking colleague or a professional author's editor, preferably with knowledge in the subject matter contained in the manuscript, to edit their manuscript before submission. A list of editing services is available at <http://journals.lww.com/jpgn/layouts/1033/oaks.journals/editservices.aspx>.

**Cover Letter:** In the cover letter provide a statement as to whether the paper was previously published in any language, including the abstract and whether the paper is currently under consideration elsewhere for publication.

**Title page:** Include on the title page (a) complete manuscript title; (b) authors' full names, in order from first to last authors; state first name (given name) then last name (family name), highest academic degrees, and affiliations; (c) name and address for correspondence, including fax number, telephone number, and email address; (d) address for reprints if different from that of corresponding author; (e) all sources of support, including pharmaceutical and industry support, that require acknowledgment; (f) the URL (website address) and trial identification number; (g) disclosure of funding received for this work from any of the following organizations: National Institutes of Health (NIH); Wellcome Trust; Howard Hughes Medical Institute (HHMI); and other(s); and (h) the word count of the manuscript body (excluding abstract except in Case Reports, keywords, references and figure legends), number of figures and number of tables.

All relevant conflicts of interest and sources of funding must also be included on the title page of the manuscript with the heading "Conflicts of Interest and Source of Funding." If there is no conflict of interest, this should also be explicitly stated as none declared.

On a separate page, list each author and his/her respective roles in the submitted work, documenting appropriate input for authorship (<http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html#two>).

**Title length:** The manuscript title should have no more than 120 characters including spaces. Keywords for referencing should be included in the title. Please no abbreviations. Fancy or comical titles are inappropriate and will be asked to be revised. Trade names of drugs and other products must not appear in the article title.

**Structured abstract and key words:** Please refer to the table above for abstract requirements for various article types. Do not cite references in the abstract. Limit the use of abbreviations and acronyms. At first mention, please write out the full term for abbreviations (e.g. Celiac Disease (CD)). Use the following subheads in your structured abstract: Objectives, Methods, Results, and Conclusions.

For Keywords, list three to five key words that are not included in the title.

**What is Known/What is New:** Immediately following the abstract (in the manuscript WORD file) for all article types except where indicated in chart above, authors should include text for a summary box that will be published on the first page of all accepted articles. This text should highlight the significance of the article with the following guidelines in mind: What is known about this subject? What are the new findings and/or what is the impact on clinical practice? Use the format:

- What is known (2-4 bullet points listed beneath this heading)
- What is new (2-4 bullet points listed beneath this heading)

The total text should not exceed 100 words. As this section should be able to stand alone, at first mention of an abbreviation, please write out the full term.

**Text:** Organize the manuscript into four main headings: Introduction, Methods, Results, and Discussion. If a brand name is cited, supply the manufacturer's name and address (city and state/country). Under Methods, include ethical approval information, if applicable.

**Data Analysis:** Description of data analyses should provide the specific methods used, their rationale, their assumptions, whether data met those assumptions, and how any missing data were handled. Try to include confidence intervals rather than or with p-values as appropriate.

**Abbreviations:** For a list of standard abbreviations, consult the Council of Biology Editors Style Guide (available from the Council of Science Editors, 9650 Rockville Pike, Bethesda, MD 20814) or other standard sources. Write out the full term for each abbreviation at its first use in abstract, what is known, manuscript body and in each table and figure unless it is a standard unit of measure.

**References:** Please adhere to the reference limits noted for each article type above. The authors are responsible for the accuracy of the references. Key the references (double-spaced) at the end of the manuscript. Cite the references in text in the order of appearance. Cite unpublished data—such as papers submitted but not yet accepted for publication and personal communications, including email communications—in parentheses in the text. If there are more than three authors, name only the first three authors and then use et al. Refer to the List of Journals Indexed in Index Medicus for abbreviations of journal names, or access the list at <http://www.nlm.nih.gov/tsd/serials/lji.html>.

### Sample references:

#### *Journal article*

1. Rautava S, Lu L, Nanthakumar NN, et al. TGF- $\beta$ 2 induces maturation of immature human intestinal epithelial cells and inhibits inflammatory cytokine responses induced via the NF- $\kappa$ B pathway. *J Pediatr Gastroenterol Nutr* 2012;54:630-8.

#### *Book chapter*

2. Todd VR. Visual information analysis: frame of reference for visual perception. In: Kramer P, Hinojosa J, eds. *Frames of Reference for Pediatric Occupational Therapy*. Philadelphia: Lippincott Williams & Wilkins; 1999:205–56.

#### *Entire Book*

3. Ming S-C, Goldman H. *Pathology of the Gastrointestinal Tract*. Philadelphia: Lippincott Williams & Wilkins; 1998.

#### *Software*

4. Epi Info [computer program]. Version 6. Atlanta: Centers for Disease Control and Prevention; 1994.

#### *Online journals*

5. Friedman SA. Preeclampsia: a review of the role of prostaglandins. *Obstet Gynecol* [serial online] January 1988;71: 22-37. Available from: BRS Information Technologies, McLean, VA. Accessed December 15, 1990.

#### *Database*

6. CANCERNET-PDQ [database online]. Bethesda, MD: National Cancer Institute; 1996. Updated March 29, 1996.

#### *World Wide Web*

7. Sullivan D. Major search engines and directories. SearchEngineWatch Web site. <http://www.searchenginewatch.com/links/article.php/2156221>. Published May 8, 2011. Accessed July 13, 2012.

### PRE-SUBMISSION CHECKLIST

Please use the following checklist to decrease the likelihood that your manuscript will be returned:









1. Title Page: Check for appropriate length and wording of the title. Title page should be on separate page from the abstract and manuscript.
2. Author and co-author information: Provide details for all of the authors/co-authors and corresponding author on the title page. The authors should be listed as: first name first, middle name second if applicable and family name last (bold surname/family name). Verify that co-author names, titles, affiliations and degrees are accurate and current.
3. On a separate page, list each author and his/her respective roles in the submitted work, documenting appropriate input for authorship (<http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html#two>).
4. Manuscript length and formatting: Check that the length of the manuscript and abstract do not exceed the maximum word count and are formatted as per instructions to authors for each. Abstract should be on a separate page from the title page and manuscript. See [Article Type Chart](#) for length and abstract guidelines.
5. Figures: Do not embed figures in manuscript. Cite the figures in the text of the manuscript. Provide figure legends on a separate page. Check that the figures and supplementary

figures are formatted as indicated in instructions to authors. Each figure should be in a separate file (uploaded individually).

6. Tables: Do not embed tables in manuscript. Cite the tables in the text of the manuscript. Provide table legends. Check that the tables and supplementary tables are formatted as indicated in instructions to authors. Each table should be in a separate file (uploaded individually).
7. References: Make sure each reference is cited in the text, references are formatted per instructions to authors and the quantity does not exceed maximum for the article type. Double check the accuracy of each reference (spelling of names, page numbers, proper journal abbreviation, etc.) as any errors are the authors' responsibility.
8. Supplementary files and appendices: Make sure files are formatted per instructions to authors and cited in main text. Add legends to figure(s) and/or table legend(s) in the manuscript or as supplementary digital content as needed.
9. JPGN requires that authors of Original Articles including Clinical Trials comply with one of the appropriate reporting guidelines endorsed by the EQUATOR Network (i.e., CONSORT, PRISMA, STARD, SQUIRE, and MOOSE). More information may be found at <http://www.equator-network.org> and <http://www.equator-network.org/library/>. For studies falling into the categories covered by these checklists, authors need to submit a formal checklist at the end of the manuscript at the time of submission. This ensures faster review turnaround since many of the points on the checklist ensure improved ease of review.
10. Ethics: Make sure to include the necessary ethical approval/clearance, clinical trial and/or parental or guardian approval information where applicable. If the submission is a clinical trial, include documentation that the project was registered in a public trials registry prior to enrollment of the first subject.
11. Permissions: If using previously published materials, include permission to re-use the material obtained from the copyright holder as Supplemental Data and acknowledge the source in your legend.
12. Reviewers: Provide names, email addresses and other pertinent information for suggested reviewers and/or non-preferred reviewers, if applicable.
13. Revised manuscripts: include a point-by-point response to the comments of each reviewer in one separate file from the marked revision. The marked revised manuscript should show the revisions with hi-lighting in yellow or red text.
14. Copyright Transfer Agreement: All co-authors must respond to the e-mail regarding authorship and answer the questionnaire. If they are unable to respond to the e-mail, they must include a completed and signed copyright transfer agreement. Submissions cannot be published without them.

## Appendix 2. Search Strategies

### PsycINFO and CINAHL

Search ID#	Search Terms	Search Options
<input type="checkbox"/> S1	 DE "Ulcerative Colitis" OR DE "irritable bowel syndrome"	<b>Search modes</b> - Boolean/Phrase
<input type="checkbox"/> S2	 TI ( "inflammatory bowel" ) OR IBD OR ( "ulcerative colitis" ) OR crohn* OR "indeterminate colitis" ) OR AB ( ("inflammatory bowel" ) OR IBD OR ("ulcerative colitis" ) OR crohn* OR "indeterminate colitis" ) OR KW ( ("inflammatory bowel" ) OR IBD OR ("ulcerative colitis" ) OR crohn* OR "indeterminate colitis" )	<b>Search modes</b> - Boolean/Phrase
<input type="checkbox"/> S3	 S1 OR S2	<b>Search modes</b> - Boolean/Phrase
<input type="checkbox"/> S4	 ((DE "Quality of Life") OR (DE "Well Being")) OR (DE "Life Satisfaction")	<b>Search modes</b> - Boolean/Phrase
<input type="checkbox"/> S5	 TI ( "quality of life" OR QOL OR HRQOL OR HR-QOL OR "life satisfaction" OR wellbeing OR well-being OR functioning) OR AB ( "quality of life" OR QOL OR HRQOL OR HR-QOL OR "life satisfaction" OR wellbeing OR well-being or functioning) OR KW ( "quality of life" OR QOL OR HRQOL OR HR-QOL OR "life satisfaction" OR wellbeing OR well-being or functioning )	<b>Search modes</b> - Boolean/Phrase
<input type="checkbox"/> S6	 S4 OR S5	<b>Search modes</b> - Boolean/Phrase
<input type="checkbox"/> S7	 S3 AND S6	<b>Search modes</b> - Boolean/Phrase
<input type="checkbox"/> S8	 S3 AND S6	<b>Limiters</b> - Publication Type: All Journals, Peer Reviewed Journal, Peer-Reviewed Status-Unknown, Dissertation Abstract, Electronic Collection

### MEDLINE (Ovid) and EMBASE

1. inflammatory bowel diseases/ or colitis, ulcerative/ or crohn disease/
2. ("inflammatory bowel" or IBD or "ulcerative colitis" or crohn\* or "indeterminate colitis").ti,ab,kw.
3. "Quality of Life"/
4. ("quality of life" or QOL or HRQOL or HR-QOL or "life satisfaction" or wellbeing or well-being or functioning).ti,ab,kw.
5. adolescent/ or child/
6. (adolesc\* or child\* or minor\* or teen\* or youth\* or young adult or young person or young people or puber\* or p?ediatric).ti,ab,kw.
7. "surveys and questionnaires"/ or self report/
8. (survey\* or questionnaire\* or measure\* or instrument\* or psychometrics or quantitative).ti,ab,kw.
9. 1 or 2
10. 3 or 4
11. 5 or 6
12. 7 or 8
13. 9 and 10 and 11 and 12

### Appendix 3. Quality Assessment Tool

Study:

	Question	Yes	No	NR, CD*	Quality rating
Quality of reporting	1. Were the aims/objectives of the study clear?				
	2. Was ethical approval or consent of participants attained?				
	3. Is it clear what was used to determine statistical significance and/or precision estimates? (e.g., p-values, confidence intervals)				
	4. Were the basic data adequately described?				
	5. Were the limitations of the study discussed?				
	6. Were the methods (including statistical methods) sufficiently described to enable them to be repeated?				
					Risk of bias rating
Selection Bias	7. Was the study population clearly defined? (Is it clear who the research was about?)				
	8. Was the selection process likely to select participants that were representative of the target population under investigation? Were inclusion and exclusion criteria applied uniformly to all participants?				
	9. Was the participation rate of eligible persons at least 50%?				
	10. Were measures undertaken to address and categorise non-responders?				
Information Bias	11. Was the psychosocial/risk factor measured using instruments/measurements that had been trialled, piloted or published previously?				
	12. Was the outcome measured using instruments/measurements that have been trialled, piloted or published previously?				
	13. Were measures implemented consistently across all study participants?				
Confounding	14. Was the study design appropriate for the stated aim (s)?				
	15. Were key potential confounding variables measured and adjusted statistically for the impact on the relationship between risk factor(s) and outcome(s)?				
Overall Quality:					

\* Not reported or cannot determine



#### Appendix 4. Item and quality ratings for each study

Question	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	Overall Quality Rating
Study																
Jelenova et al. (2016)	Y	Y	Y	Y	Y	Y	Y	CD	CD	CD	Y	Y	Y	Y	N	Low
	Quality of reporting: Moderate						Selection bias: Moderate				Information bias: Low			Confounding: High		
Reed-Knight et al. (2016)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High
	Quality of reporting: High						Selection bias: Low				Information bias: Low			Confounding: Low		
Loreaux et al. (2015)	Y	Y	Y	Y	Y	Y	Y	Y	N	NR	Y	Y	N	Y	Y	Moderate
	Quality of reporting: High						Selection bias: Moderate				Information bias: Low			Confounding: Low		
Engelmann et al. (2014)	Y	Y	Y	Y	Y	Y	Y	Y	Y	N/A	Y	Y	Y	Y	Y	High
	Quality of reporting: High						Selection bias: Low				Information bias: Low			Confounding: Low		
Gumidyala & Greenley (2013)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	High
	Quality of reporting: High						Selection bias: Low				Information bias: Low			Confounding: Low		
Mackner et al. (2012)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	High
	Quality of reporting: High						Selection bias: Low				Information bias: Low			Confounding: Low		
Gray et al. (2011)	Y	Y	Y	Y	Y	Y	Y	CD	Y	CD	Y	Y	CD	Y	Y	Moderate
	Quality of reporting: Moderate						Selection bias: Moderate				Information bias: Low			Confounding: Low		
Herzer et al. (2011a)	Y	Y	Y	Y	Y	Y	Y	Y	Y	CD	Y	Y	CD	Y	Y	High
	Quality of reporting: High						Selection bias: Low				Information bias: Low			Confounding: Low		

Question	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	Overall Quality Rating
Study																
Herzer et al. (2011b)	Y	Y	Y	Y	Y	Y	Y	Y	Y	CD	Y	Y	CD	Y	Y	High
	Quality of reporting: High						Selection bias: Low				Information bias: Low			Confounding: Low		
De Boer et al. (2005)	Y	CD	Y	Y	Y	Y	Y	CD	N	NR	Y	Y	Y	Y	Y	Moderate
	Quality of reporting: Moderate						Selection bias: Moderate				Information bias: Low			Confounding: Low		
Van der Zaag-Loonen (2004)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High
	Quality of reporting: High						Selection bias: Low				Information bias: Low			Confounding: Low		
MacPhee et al. (1998)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	No	Low
	Quality of reporting: High						Selection bias: Low				Information bias: Low			Confounding: High		
Abbreviations: Y = Yes; N = No; CD = Cannot determine; NR = Not reported; N/A = Not applicable																

## Appendix 5. PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5-6
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	PROSPERO CRD42017077188
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	6-7
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	6
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	38
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6-7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	/
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	7-8
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	/
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	8

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	7-8
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	/
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	8-9
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	12-14
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	15-16 & 40-41
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	12-14
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	17-20
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	15-16
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	/
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	21-23
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	24
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	23-25
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	/

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: [www.prisma-statement.org](http://www.prisma-statement.org).

## Appendix 6. Letters of Approval (REC and R & D)



### Health Research Authority

#### North West - Preston Research Ethics Committee

Barlow House  
3rd Floor  
4 Minshull Street  
Manchester  
M1 3DZ

Telephone: 020 71048008

20 June 2017 revised

Dr Alison Jackson  
Institute of Health and Wellbeing, College of Medical, Veterinary and Life Sciences  
University of Glasgow  
First Floor Admin Building, Gartnavel Royal Hospital 1055 Great Western Road, Glasgow  
G12 0XH

Dear Dr Jackson

<b>Study title:</b>	<b>Exploration of transition experiences of adolescents and young adults with IBD</b>
<b>REC reference:</b>	<b>17/NW/0391</b>
<b>IRAS project ID:</b>	<b>223577</b>

Thank you for responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net) outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

#### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of

the study at the site concerned.

*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*

*Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations.*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

### Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper	1	08 June 2017
Covering letter on headed paper		09 June 2017
GP/consultant information sheets or letters	2	30 May 2017
Interview schedules or topic guides for participants	1	09 January 2017
Letters of invitation to participant [reminder]	3	16 June 2017
Letters of invitation to participant	2	15 May 2017
Other [Self-help Resource Sheet for participants]	1	15 May 2017
Other [Participant Response Form]	2	27 April 2017
Other [Cover Letter in Response to Provisional Opinion]		19 June 2017
Participant consent form	3	15 May 2017
Participant information sheet (PIS)	7	19 June 2017
REC Application Form [REC_Form_09062017]		09 June 2017
Research protocol or project proposal	6	15 May 2017
Summary CV for Chief Investigator (CI)		28 April 2017
Summary CV for student		
Summary CV for supervisor (student research)		28 April 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language	2	09 June 2017

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

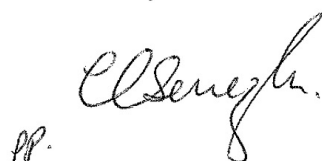
We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

**17/NW/0391**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely



**Dr Rob Monks**  
**Chair**

Email: [nrescommittee.northwest-preston@nhs.net](mailto:nrescommittee.northwest-preston@nhs.net)

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Ms Emma Jane Gault*

*Elaine O'Neill, NHS Greater Glasgow and Clyde - Research and Development*



Administrator: Mrs Elaine O'Neill  
Telephone Number: 0141 232 1815  
E-Mail: [elaine.o'neill2@ggc.scot.nhs.uk](mailto:elaine.o'neill2@ggc.scot.nhs.uk)  
Website: [www.nhsggc.org.uk/r&d](http://www.nhsggc.org.uk/r&d)

R&D Management Office  
West Glasgow ACH  
Dalnair Street  
Glasgow G3 8SW

29 June 2017

Mrs Isabelle Kolte  
Trainee Clinical Psychologist  
NHS GG&C  
North Learning Disability Team  
Stobhill Hospital  
133 Balornock Road  
Glasgow G21 3UW

### NHS GG&C Board Approval

Dear Mrs I Kolte,

<b>Study Title:</b>	Exploration of transition experiences of adolescents and young adults with IBD
<b>Principal Investigator:</b>	Mrs Isabelle Holte
<b>GG&amp;C HB site</b>	Queen Elizabeth University Hospital & the Royal Hospital for Children
<b>Sponsor</b>	NHS Greater Glasgow and Clyde
<b>R&amp;D reference:</b>	GN17GA243
<b>REC reference:</b>	17/NW/0391
<b>Protocol no:</b>	V6; 15/05/17

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

#### Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
  - a. During the life span of the study GGHB requires the following information relating to this site
    - i. Notification of any potential serious breaches.
    - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy ([www.nhsggc.org.uk/content/default.asp?page=s1411](http://www.nhsggc.org.uk/content/default.asp?page=s1411)), evidence of such training to be filed in the site file.

2. **For all studies** the following information is required during their lifespan.
  - a. Recruitment Numbers on a monthly basis
  - b. Any change of staff named on the original SSI form
  - c. Any amendments – Substantial or Non Substantial
  - d. Notification of Trial/study end including final recruitment figures
  - e. Final Report & Copies of Publications/Abstracts

**Please add this approval to your study file as this letter may be subject to audit and monitoring.**

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,



Mrs Elaine O'Neill  
**Senior Research Administrator**

**Cc:** Ms Emma-Jane Gault

## Appendix 7. Research Pack

Invitation Letter Version 2 (15.05.17)



### INVITATION LETTER

Gastroenterology Service  
Queen Elizabeth University Hospital  
1345 Govan Road  
Glasgow  
G51 4TF

Dear [patient name]

A research study is taking place at the Gastroenterology Service at Queen Elizabeth University Hospital. The researcher, Isabelle Kolte, is a Trainee Clinical Psychologist with the University of Glasgow. As part of her Doctorate in Clinical Psychology she is conducting a research project in partnership with NHS Greater Glasgow and Clyde Gastroenterology Services.

She is interested in finding out more about what it is like for young people with Inflammatory Bowel Disease (IBD) when they transfer from child to adult gastroenterology services and how this affects their day to day life. The enclosed information sheet provides more detailed information about the study.

Thank you for taking the time to read this invitation.

If you would like to take part in the study please fill in and return the Participant Response Form or if you would like more information please contact the researcher. Details on how to do this are provided at the end of the information sheet.

Yours sincerely

Dr John Paul Seenan

**Consultant Gastroenterologist**

Queen Elizabeth University Hospital  
1345 Govan Road  
Glasgow  
G51 4TF  
Telephone: 0141 451 6089



## PARTICIPANT INFORMATION SHEET

**Title of Project:** Exploration of transition experiences of adolescents and young adults with IBD

**Name of Primary Researcher:** Isabelle Kolte (Trainee Clinical Psychologist)

**Contact Details for the Primary Researcher, Research Supervisor and Independent Contact for the Project can be found at the end of the Information Sheet.**

I would like to ask you to take a few minutes to read over this information sheet. My name is Isabelle Kolte and I am a Trainee Clinical Psychologist with the University of Glasgow. As part of my Doctorate in Clinical Psychology I am conducting a research project in partnership with NHS Greater Glasgow and Clyde gastroenterology services.

I am contacting you to ask if you would like to take part in this research study. This leaflet is designed to give you all the information that you need to decide if you want to take part. If you have any questions about the research or want to talk to me about it, you can contact me (my phone number and address are at the bottom of this leaflet).

### What is the study about?

The study wants to find out what it is like for young people with IBD to transfer from child to adult hospitals. Healthcare transition often happens during a time of other transition experiences such as graduating from secondary school, entering higher education or starting to work and leaving home. The study is interested in finding out about young people's experiences during this time when a number of transitions happen and how this affects their day to day life. We know that there is some research on transitioning from child to adult IBD care, for example research that explored the needs of young people during transfer or factors that support or hinder successful transition. This research has helped services to improve their transitional care. Most of this existing research however looked at the opinions of experts, parents or people who provide services like doctors and nurses. There is not a lot of research on how teenagers or young adults themselves feel when they move from child to adult services. This is why this research is being carried out, to find out about the opinions of teenagers and young adults.

### Why have I been invited?

You have been invited to take part in this research because you are a teenager or young adult with a diagnosis of IBD who is currently moving from a child to an adult gastroenterology service or has completed this move within the past 24 months. The researcher hopes to hear about your experiences during the time of transition.

#### How is the research being monitored?

The study was reviewed and approved by an independent group of people called the West of Scotland Research Ethics Committee to confirm that the 'the rights, safety, dignity and well-being of people participating in research are safeguarded'. The study has also been reviewed by the local Research and Development Department and the University of Glasgow Mental Health and Wellbeing Department.

The progress of this research is being monitored by the researcher's clinical and academic supervisors.

#### What will I be asked to do?

You will be asked to meet with the researcher to talk about how IBD affects your day to day life and how it was like for you to transfer from child to the adult hospitals.

To start with, you will be asked to fill in the *Participant Response Form* (included in this pack) to let the researcher know whether you want to take part in this study and to send it back to the researcher in the freepost envelope.

If you choose to take part, the researcher will arrange to meet with you at Queen Elizabeth University Hospital where you probably attended at least one of your transition appointments. The interview will take 45 – 60 minutes. At the beginning of the interview you will be asked to sign a consent form and to give your permission for the interview to be recorded. Recordings are made to allow analysis of the interviews. The interviewer will then ask you several questions. All interviews will be anonymised when the researcher transcribes them, so all details that could identify you will be taken out. Any direct quotes from your interview will also be anonymised.

Interviews are arranged for a time that is suitable to you.

#### Confidentiality

The purpose of the interview is to find out about your transition experiences, and the questions asked during the interview are designed to enable a discussion about these experiences. However, it is important to know that if you share information that makes the researcher concerned about your safety or the safety of another person, she may be required to talk to others involved in your care. She will not do this without speaking to you about this first. Other than for these reasons, the discussions during the interview will be kept confidential and the interview transcripts will be anonymised so others will not be able to determine which of the answers were yours.

A standard letter will be sent out to your GP informing them of your participation in the study. However, the content of the interview will be kept confidential.

Representatives of the study sponsor, NHS GGC, may look at your information to ensure that the study is being conducted properly.

#### Do I have to take part?

No, you do not have to take part in the research. Your choice to take part or not will not affect any medical service or treatment you are receiving.

You can change your mind about taking part at any time and do not have to tell the researcher why. If you decide to withdraw, the data collected from you up to your withdrawal will be used unless you specifically tell the researcher not to.

You can also refuse to answer any questions you don't feel comfortable with.

#### What are the possible risks and benefits of taking part?

Your taking part in this study is not considered as a risk. However, for some people talking about their transition experiences may be upsetting. If you do become upset at any point, you will be offered a break and the interviewer will check with you whether you want to continue the interview. If appropriate, you will be signposted to services that may be able to offer additional support.

There will not be any direct benefits for you from taking part in this study. However, if healthcare professionals have a better understanding of the experiences of young people with IBD as they transfer from paediatric to adult care, services could be designed more sensitively to meet their needs, thus improving their transition experiences and health outcomes.

#### What happens to the information?

Information are kept safely in accordance with the Data Protection Act (1998). Your identity and personal information are completely confidential and known only to the researcher. All personal information will be stored on a secure NHS computer. Audio recordings from the interview will be stored on an encrypted University laptop and destroyed once the transcription is completed. During transcription, the information you give to the researcher will be anonymised, this means that no-one will know which answers were yours.

After the interview, the researcher will compare what you say to others who have taken part. This will be written up as part of the University research thesis and marked. With your permission, anonymised quotes from the interview will be used in the write up. A copy of the final thesis will be deposited on Enlighten, the University of Glasgow research data repository and the study may also be published in a scientific journal.

If you are interested in finding out about the results of the study, you can indicate that you would like to receive a summary of the findings on the consent form. The summary will be posted to you once the thesis is completed.

#### Complaints Procedure

If you decide to take part in the study and become unhappy with anything during this process, you are entitled to make an official complaint by contacting the local Complaints Team or the

Patient Advice & Support Service on the details below:

NHS Greater Glasgow and Clyde Complaints Team  
Phone: 0141 201 4500  
E-Mail: [complaints@ggc.scot.nhs.uk](mailto:complaints@ggc.scot.nhs.uk)

Patient Advice & Support Service  
Phone: 0800 917 2127  
E-mail: Fill a contact form accessible on: <http://www.cas.org.uk/pass>

What if I have any further questions about the study?

If you have any further questions about the study or the information provided, you can contact the researcher. Her contact details are listed at the end of this information sheet.

You can also use the Participant Response Form to indicate that you would like to find out more about the study. The researcher would then contact you by telephone to talk about the study and answer your questions.

If I want to take part, what do I do next?

1. Read all the information.
2. Talk to your parents about the information if you want to.
3. Decide if you want to take part.
4. Fill in the **Participant Response Form** including your name and how you would like the researcher to contact you.
5. Send the form back to the researcher in the envelope provided. As this is a Freepost address you do not need to put a stamp on it.
6. When the form is received, the researcher will contact you to arrange an interview.
7. When you come to the interview the researcher will ask you to fill in a *Consent Form* which says that you have decided to take part in the study.
8. Please note that there is a chance that you are not invited for an interview if there are too many people who volunteer to participate. Participants are chosen on a first come first serve basis.

Thank you for taking the time to read this information sheet and for any further participation you may have.

**Isabelle Kolte**  
**Trainee Clinical Psychologist**  
**Contact Details:**

Researcher:

Isabelle Kolte, Trainee Clinical Psychologist  
Institute of Health and Wellbeing  
University of Glasgow  
Administration Building  
Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow, G12 0XH  
Tel: 0141 201 0803  
[i.kolte.1@research.gla.ac.uk](mailto:i.kolte.1@research.gla.ac.uk)

Academic Supervisor:

Dr Alison Jackson, Senior Lecturer  
Institute of Health and Wellbeing  
University of Glasgow  
Administration Building  
Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow, G12 0XH  
Tel: 0141 211 3917  
[Alison.Jackson@glasgow.ac.uk](mailto:Alison.Jackson@glasgow.ac.uk)

Project Supervisor:

Dr Mary Cawley, Clinical Psychologist  
Glasgow Liaison Psychiatry Service  
Queen Elizabeth University Hospital  
Office Block  
1345 Govan Road  
Glasgow G51 4TF  
Tel: 0141 201 2422 (secretary)  
[Mary.Cawley@ggc.scot.nhs.uk](mailto:Mary.Cawley@ggc.scot.nhs.uk)

Independent Contact:

Dr Tom McMillan  
Institute of Health and Wellbeing  
University of Glasgow  
Administration Building  
Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow, G12 0XH  
Tel: 0141 211 0354  
[Thomas.McMillan@glasgow.ac.uk](mailto:Thomas.McMillan@glasgow.ac.uk)





**PARTICIPANT RESPONSE FORM**

**Title of Project:** Exploration of transition experiences of adolescents and young adults with IBD

**Name of Primary Researcher:** Isabelle Kolte (Trainee Clinical Psychologist)

*Please tick*

I have read the *Participant Information Sheet* and would like to find out more about the study. Please contact me by telephone to talk about the study.

☐

I am happy to be contacted by telephone to talk about the study and arrange an interview

☐

It is ok for the researcher (Isabelle Kolte) to leave a message if I don't answer the phone.

☐

**Name (please print in block capitals):**

**Telephone number:**

## Appendix 8. Reminder Letter Version 4 (30.05.17)



### REMINDER LETTER

Gastroenterology Service  
Queen Elizabeth University Hospital  
1345 Govan Road  
Glasgow  
G51 4TF

Dear [patient name]

About a month ago you received a letter inviting you to participate in a research study that is taking place at the Gastroenterology Service at Queen Elizabeth University Hospital. The study is still recruiting.

The study is being carried out by Isabelle Kolte, Trainee Clinical Psychologist with the University of Glasgow as part of her Doctorate in Clinical Psychology and in partnership with NHS Greater Glasgow and Clyde Gastroenterology Services. She is interested in finding out what it is like for young people with Inflammatory Bowel Disease (IBD) when they transfer from child to adult gastroenterology services and how this affects their day to day life.

The enclosed information sheet provides more detailed information about the study. If you would like to take part please fill in and return the Participant Response Form or contact the researcher on 0141 201 0803 (University of Glasgow) or send an email to [i.kolte.1@research.gla.ac.uk](mailto:i.kolte.1@research.gla.ac.uk). Please ignore this letter, if you have already responded to the invitation.

Thank you for taking the time to read this invitation. No further reminder letters will be sent to you.

Yours sincerely

Dr John Paul Seenan

**Consultant Gastroenterologist**

Queen Elizabeth University Hospital  
1345 Govan Road  
Glasgow  
G51 4TF  
Telephone: 0141 451 6089

Reminder Letter Version 1 (01.05.2017)

## Appendix 9. Consent Form Version 3 (15.05.17)



### CONSENT FORM FOR PARTICIPANTS

**Title of Project:** Exploration of transition experiences of adolescents and young adults with IBD

**Name of Primary Researcher:** Isabelle Kolte (Trainee Clinical Psychologist)

*Please initial box*

1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that data collected during the study, may be looked at by individuals from NHS Greater Glasgow and Clyde, from regulatory authorities or from the NHS Health Boards in Scotland where it is relevant to my taking part in this research. I give permission for these individuals to have access to these data. ☐
4. I understand that this research is part of a University course. ☐
5. I understand that it will be written up as part of a research project and possibly published and that my name will not be on it. ☐
6. I agree to the recording of the interview and I understand that the transcript will be anonymised. ☐

IRAS Project ID 223577

7. I give permission for my GP and consultant gastroenterologist to be informed of my participation in the study.

☐

8. I agree to the use of anonymised quotes.

☐

9. I would like to receive a summary of the research findings once the research is completed.

☐

10. I agree to take part in the above study.

_____ Name of Participant	_____ Date	_____ Signature
_____ Name of Person taking consent	_____ Date	_____ Signature

IRAS Project ID 223577

## Appendix 10. Interview Schedule Version 1 (09.01.17)



### INTERVIEW SCHEDULE

**Title of Project:** Exploration of transition experiences of adolescents with IBD

**Name of Primary Researcher:** Isabelle Kolte (Trainee Clinical Psychologist).

Hello, I am Isabelle Kolte, I am a trainee clinical psychologist. Thank you very much for agreeing to talk to me and for making the time to come here today. As you know from the information sheet you received, I am interested in finding out what it is like for young people who have IBD to transfer from child to adult gastroenterology services. I am not part of the medical gastroenterology team and all information from the interview that could identify you as a person will be removed when I write up the research, so that your answers remain confidential. I am interested in hearing both about positive experiences, things that were helpful during transition but also negative experiences or things that were not helpful.

I have prepared some questions I would like to ask you about your experiences. This should take about 45 minutes. But before we start there are a few formalities to get out of the way.

The research pack I sent out contained an information sheet. Have you read through the information sheet? Do you have any questions?

We also need to sign the consent form. Do you have any questions?

(Sign Consent Form)

Do you remember from the information sheet you received that I would like to record what we talk about so that I can write up our conversation word for word. Is that still ok with you? The recording will be downloaded onto an encrypted laptop. Only my University supervisor and I would listen to it and as I said before all information that could identify you will be removed when it's written out.

I will now switch on the recorder.

### **Introduction**

Before I ask you about your transition experiences, I would like to find out a bit about you.  
Can you tell me a bit more about your condition?

#### **Prompts:**

- What form of IBD do you have? (UC, Crohn's or IBDU)
- Is there anyone else in your family who has IBD?
- Are you currently attending appointments with any NHS gastroenterology service?
- Do you currently receive any treatment for your IBD?
- How old were you when you found out you have IBD?
- Have you completed your transition to adult care?
  - If yes, when?
  - If not, when did you start transitioning?

### **General experiences of being a young person with IBD**

How has it been like for you being a young person with ... (use diagnosis)?

How does IBD affect your day to day life?

#### **Prompts**

- How has it impacted your relationships with friends, family?
- How has it impacted you in school/at work?
- How has it impacted your day to day activities or hobbies?
- How has it impacted how you see yourself?
- How has it impacted how other people see you?

How have these experiences changed over time, as you were getting older?

### **Experiences with Children's Services**

How is/was it like to go to clinics at the children's hospital?

#### **Prompts**

- How does/did it feel going there?
- What do/did you think about it?
- What do/did you like?
- What don't/didn't you not like?
- What do/did you think about the professionals, resources, support?

### **Experiences during transition**

What was it like for you to transfer from the children to the adult hospital?

#### **Prompts**

- How do/did you feel about the transfer?
- Do/did you have any specific concerns or worries (at the time)?
- How prepared do/did you feel?
- What made you feel ready/not ready?
- Who was there to support you at that time, professionals, family, friends?
- Who did you talk to about the transition, friends, family, professionals?

How does/did the transition impact you?

#### **Prompts**

- How did it impact your day to day life?
- How did it impact your school/work, friendships, activities outside school/work?
- How did it affect the management of your IBD?

What about your parents? How is/was it like for them during transition?

You told me that your parents ... How is/was that like for you? How does/did that affect you?

### **The NHS GGC Transition Process**

What do you think about the NHS GGC transition process?

#### **Prompts**

- What is/was helpful about the way it was set up?
- What is/was unhelpful about the way it was set up?

How could the transition the transition process be improved?

If someone you knew would have to go through the process, what would be helpful for them? What advice would you give them?

#### **Prompts**

- What do you think about the support that was offered?
- What do you think about the location?
- What do you think about the timing?
- What was missing?

**Ending**

Is there anything that we haven't talked about that you would like to mention?

Anything that I haven't asked about that you think is important for me to know?

Thank you for taking the time to talk to me today and for talking about your experiences so openly.



## Appendix 11. Sample of Analysed Transcript

Emergent themes	Original transcript	Exploratory comments
Impact of diagnosis - friendships	<p>I: So, who were those people?</p> <p>02: They were friends who are my friends now, they were, they kind of picked up the tab and saw how, they were, we were friends before but not as close. Um, they obviously saw like how, not badly I was being treated but how I wasn't being treated how they would have treated me. Um, so that really helped a lot having other people know like that they shouldn't be treating me like this after just coming out of hospital and being so unwell.</p> <p>I: So, how do you think things changed for you after that?</p> <p>02: Yeah, definitely, I think that really made me grow up a lot, just in general to be like if they don't wanna be there that's fine, like.</p> <p>I: Ok, and your journey after that how has it been, how has your physical health been since that hospital admission?</p> <p>02: Yeah, it's been good, that was just the one (emphasized) down but it's been up since then, um when I weaned off my steroids it was fine, um because the medication I'm on is like plan D medication, um but yeah everything's going fine.</p> <p>I: Ok. So, do you think that right now there is not much of an impact of the disease on your day to day life?</p> <p>02: Yeah, uh-huh. Yes, I'd say it's pretty normal.</p>	<p><i>Tone of voice: It appears like she struggles to express herself – could suggest that this still is an emotionally loaded topic</i></p> <p><i>Metaphor: They picked up the tab; it appears that she feels let down by her friends; she indicates an expectation that was disappointed. It sounds like a painful experience</i></p> <p>It appears that it helped her that her perception of the situation was validated by her friends; they also felt that she should not have been treated like this.</p> <p>She appears to try and make sense of the experience; maybe identify something positive that came out of this difficult experience &gt; made me grow up; she says 'that's fine'; has there been a change over time? It is fine now, reflecting back; is she denying or minimising the emotional experience</p> <p>Contextualises her experience in journey over time; it's been good compared to that initial "down" experience On medication ; "D medication" implies there has been some trial of different medications over time.</p> <p><i>Interviewer question was suggestive; could have used an open-ended question: how does IBD impact your life right now?</i></p>

Feelings about transition	<p>I: So, at the time when you were first diagnosed you were a teenager and with children services and you described that you also were in the children's hospital. How's it been like in children services for you?</p> <p>O2: I think it was more comforting in children's because they were the ones who diagnosed me, and the adults had like, not misdiagnosed me, but didn't know the specifics of it, so I suppose when I, when I was told that we were going to start transitioning I was a wee bit wary. I was like, oh they didn't know what it was at first, I was a bit, a bit on edge about it. But the transition, the first transition meeting I had last week that was a lot more reassuring, made me like at ease about it.</p>	<p>"pretty" normal; what does pretty mean? A follow up question here would have been helpful Pretty may suggest that there are still things that are not normal; what are those things?</p>
Overlap in care – joint appointments	<p>I: What made it reassuring?</p> <p>O2: Because it was the children's hospital in the driver seat like asking the questions and just, um like um the man from the adult t hospital just sitting back and like listening and like getting to know me a little bit. Um, and it wasn't like jumped straight in, to adult.</p>	<p>It implies that she trusted Children's hospital staff; medical expertise appears important facilitator of trust – trust appears to make her feel comfortable; hint at previous contact with adult services: she indicates that she does not trust their medical expertise as much as they struggled to make an initial diagnosis; this past experience shapes her response to transition; she feels on edge and vary</p> <p>She indicates a critical sense of time: <i>at first</i> I was a wee bit wary, a bit on edge about it; it may indicate that her feelings changed over time</p> <p>Transition meetings &gt; there is an overlap in care provision; joint appointments &gt; these offer reassurance (she now feels more at ease about it) &gt; it appears that the overlap facilitated a change in emotion</p>
Overlap in care – joint appointments		
New relationships – not knowing each other	<p>I: Ok. So, I'm hearing that it's maybe the joint appointments that are helpful?</p> <p>O2: Yeah.</p> <p>I: So, can you tell me a little more about how you liked it in Children's services, what you maybe liked about it?</p> <p>O2: I like the friendly nature of it they are not, it's very, obviously working with like really young kids they have to make it (paused) easy for them to understand so when I was in the hospital it was, I suppose not dumped down but it</p>	<p>It appears that it is reassuring that adult hospital is not just "taking over"; she appears to appreciate that they were listening to Children's hospital staff; that they made an effort to get to know her; it implies that being "stranger"/not knowing each other may be challenging? She refers to transition as a process; there was no abrupt end to her paediatric care</p> <p><i>Somewhat suggestive; could have been a neutral open-ended question: How was it like?</i></p>

Experience in Children's hospital – developmentally appropriate service delivery	<p>was very very basic and what they said they made, they would, they would explain to me as they would maybe would to a five year old or six year old, so I could fully fully understand it and I, I liked that a lot.</p> <p>I: Ok, so it seems like they really made things very clear for you and that was helpful at the time.</p> <p>02: Yeah.</p> <p>I: Ok, is there anything else that you can think of that you really liked about it?</p> <p>02: Just the way they go about things. Um, the way she explained it to me, she got a book and she was like explaining all the different parts of the like the disease and how it affects everyone else and meeting with the dieticians, just everyone (emphasized), every different person that plays a role, meets you at some point.</p>	<p>She talks about positive experiences in Children's hospital; she liked that it was friendly; she appears to like the information she was provided with and that they were age-appropriate; she indicates that understanding of IB/medical care is important to her</p> <p>Patient care in children's – Provision of information - they explain it so I could fully fully understand it – I liked that a lot</p>
Experience in Children's hospital – MDT service delivery	<p>I: So, lots of different professionals in the team?</p> <p>02: Yeah, yeah.</p> <p>I: So, who were some of the people you met over the years?</p> <p>02: The dietician, the consultants and the IBD nurses were the main ones</p> <p>I: Ok. And is there anything you can think of that you thought was unhelpful or that you didn't like?</p> <p>02: No, not that I can think of.</p>	<p>Again: it appears that there is a real appreciation of being provided with information that are accessible</p> <p>She indicates that there is a MDT model of service delivery; meet with different professionals that play a role at some point</p> <p>Make-up of MDT team: dietician, consultant, IBD nurses</p>

<p>Feelings about transition Overlap in care – transition is a process</p> <p>Change in feelings over time</p> <p>Contrasting Children’s and adult hospital – differences</p>	<p>I: Ok. And then you mentioned that transition was brought up when you were 16?</p> <p>O2: Yeah.</p> <p>I: And how did you feel about it at that point?</p> <p>O2: Yeah, I was a bit wary because of them not being able to diagnose me. I was like, oh, ok but I knew it was just, it is going to come up at some point, they are just mentioning it to me now, to say maybe within the next year or so you’ll have a couple of meetings and then maybe you’ll be gone, maybe you’ll stay on longer, um yeah, but it was a bit daunting at first</p> <p>I: Ok. And, what were your concerns or worries about the transition?</p> <p>O2: That I, not that I wasn’t getting as much attention, but that they weren’t gonna (pause) support me as much as the children's hospital did. (pause)</p> <p>I: Any more thoughts around that? I’m waiting because I can see that you are still thinking.</p> <p>O2: Yeah, because obviously children need a lot more support than adults but as much as I’m like becoming an adult I’m still (pauses) a child in the same sense, I was a bit, I don’t wanna to be left on my own.</p> <p>I: Ok. So, you’re talking about being left on your own, what’s the worry here?</p>	<p>Start of discussion about transition process</p> <p>Expresses initial feelings about transition: wary, daunting – refers back to the lack of trust in adult services due to previous negative experience; this appeared to have been a significant experience for her She indicates again that transition is a process that occurs over time; she indicates that there will be an overlap in care provision (a couple of joint meetings); she indicates that there is no predetermined duration for the process &gt;&gt; maybe gone or maybe stay a bit longer; I wonder how that feels? Is that a good thing or does that increase uncertainty? Daunting at first: she again indicates that this was an initial response; how did this response change over time? Emotional versus cognitive response: I knew it is going to come up at some point – it appears like she was expecting it; she may have thought about it before</p> <p>Discusses her worries about how adult care may be different; it appears that she has ideas about how adult hospital may be like; she fears a reduction in support</p> <p><i>Pause: She hesitates – is she thinking about the question/her answer or does it indicate that this is an emotional topic for her?</i></p> <p>She refers to adolescence as an in-between developmental stage; she indicates that the move from child to adult is also a transition that takes time; she indicates that adolescents are not adults, they need additional/different support than fully-grown adults; it appears that she indicates a fear that her</p>
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Losing close relationships		<p>developmental needs may not be met in adult services; she expresses a fear about losing support; not being supervised as closely</p> <p>Children's services is portrayed/experienced as a 'family like' environment (close net, small numbers); is there a sense of loss?; again: reference to now being as well supported; maybe not being as 'important' as one in many patients; reference to knew relationships with professionals</p>
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## **Abstract**

*Background:* With increasing numbers of paediatric-onset Inflammatory Bowel Disease (IBD), more patients will eventually need to transfer from paediatric to adult care and consequently, transition has become an important concern for healthcare providers. Numerous recommendations are available, but these have predominantly been informed by expert, clinician and parent opinions. To date, no high-quality study has exclusively investigated the opinions of young people with IBD themselves.

*Aims:* The aim of this study is to explore the transition experiences of young people with IBD from their perspective, using Interpretative Phenomenological Analysis.

*Methods:* 4-10 participants aged 16 years and above with IBD will be recruited from NHS Greater Glasgow and Clyde gastroenterology services. Each participant will complete an in-depth interview, exploring their experiences during transition.

*Applications:* The findings of this study may help to identify potential service improvements for transitioning young people with IBD from paediatric to adult gastroenterology services.

## **1. Introduction**

### **1.1 Background**

Inflammatory bowel disease (IBD) is a chronic relapsing and remitting condition in which parts of the intestines become swollen, inflamed and ulcerated. The two main forms of IBD are Crohn's Disease (CD) and Ulcerative Colitis (UC). They differ mainly in the areas of the digestive system affected. While UC affects the large intestine and the rectum, CD may affect any part of the digestive system from

mouth to anus. In a minority of patients, it is unclear which type is present and a diagnosis of IBD unclassified is given. The exact cause of IBD is still not known, but researchers believe that it involves an interaction between genes, the immune system and environmental factors. Symptoms of IBD vary from person to person and in severity, but can include cramping pain in the abdomen, diarrhoea, loss of weight, anaemia, tiredness and lack of energy. Some people also experience swollen joints, mouth ulcers, inflamed eyes, skin rashes, liver problems and there can be an increased risk of osteoporosis and bowel cancer. Most patients go through intermittent and unpredictable periods when the disease is active and periods of better health with few or no symptoms (Crohn's & Colitis UK, 2016a; Crohn's & Colitis Foundation of America (CCFA), 2014). Drug treatment or surgery can reduce or control symptoms and people with IBD can, and do live full and productive lives. However, many people find that the condition or their disease concerns affects their quality of life because they can interfere with daily activities, responsibilities, work or education, limit the person's lifestyle and disrupt relationships (Gosh & Mitchell, 2007; Cole et al. 2015; De Rooy et al., 2001).

With an IBD population of 26,000 people, Scotland has the highest prevalence of IBD in the UK and the highest regional incidence rate with 0.65 per 10,000 per year (Crohn's & Colitis UK, 2016b). Although IBD can develop at any age, up to 25% is diagnosed in childhood and adolescence, and data suggests that the incidence of paediatric-onset IBD is rising worldwide (Leung et al., 2011). Recent Scottish data showed that the incidence of paediatric IBD<sup>1</sup> has increased by about 76% from 4.5/100 000/year in 1990-1995 to 7.8/100 000/year in 2003-2008.

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<sup>1</sup> IBD diagnosed in subjects less than 16 years of age

Lifestyle changes including low-fibre, high-sugar diets, plus rising obesity rates as well as bacteria and domestic hygiene have been suggested as possible causes (Henderson & Wilson, 2012). Paediatric-onset IBD may have a more complicated and severe course than adulthood-onset IBD and the burden of chronic IBD has significant effects on growth, education, future employment and psychosocial wellbeing (CCFA, 2014; Henderson & Wilson, 2012).

## **1.2 Health Care Transition**

The term transition is used to describe the process whereby a young adult<sup>2</sup> is transferred from paediatric to adult care. Readiness for entry into the transition process is assessed based on several criteria, including age (>14 years), physical and psychological maturity and physical health status (West of Scotland Paediatric Gastroenterology, Hepatology and Nutrition (WoSPGHaN), 2014). The goal of transition is to ensure continuity of care by preparing the young adult and their families for the adult system and by facilitating successful engagement with adult services. With increasing numbers of paediatric-onset IBD, more patients will eventually need to transition to adult services. Consequently, it has become an important concern for healthcare provider to better understand issues related to this process (Leung et al., 2011). Due to inherent differences in paediatric and adult service cultures, transition can pose challenges for young adults, their parents and healthcare professionals. While paediatric hospitals have a family-centred, multidisciplinary setup with parental involvement, adult services focus on the individual patient and expect greater independence and self-management on the part of the patient (Bollegala & Nguyen, 2015; Cole et al., 2015).

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<sup>2</sup> The literature on transition from paediatric to adult care uses a variety of terms including adolescent, young adult and youth, often without an explicit definition or reference to age. Subsequently the term 'young adult' will be used broadly to comprise different terminology.



Additionally, healthcare transition often coincides with a multitude of developmental and psychosocial transition experiences such as graduating from secondary school, entering higher education or starting to work and leaving home (Bollegala & Nguyen, 2015). There is concern that reduced parental oversight, lacking knowledge of IBD and noncompliance related to the developmental profile of adolescence, puts young adults with IBD at risk of adverse clinical outcomes (Bollegala & Nguyen, 2015). Gastroenterologists observed deficits in young adult's knowledge of IBD and its treatment, their medical history and self-advocacy as key problems during transition (Sebastian et al, 2012; Hait et al, 2009). Research further indicates that young adults with IBD demonstrate poorer self-management including low adherence to medication and lower clinic attendance than their adult counterparts (Cole et al, 2015; Goodhand et al, 2010). Goodhand et al (2010) compared compliance in 100 adolescents with adult controls and found that adolescents missed a median number of 20% of their appointments compared with 0% in adults ( $p < 0.0001$ ). Cole et al (2015) conducted a retrospective review of records of 72 patients whose IBD was diagnosed in paediatric care and found that 28% of patients were noncompliant to medications during transition (median age at transition = 18 years, range 16-21). It is widely acknowledged that lower healthcare utilization and nonadherence to medication can result in poor health outcomes (Paine et al, 2014 and Leung et al, 2011).

To reduce further distress caused by these multi-faceted transition experiences and to ensure that the transition process is both effective and successful, it is important to gain a better understanding of young adult's needs during transfer. Quantitative and qualitative studies have investigated the needs of young people with IBD as well as barriers to successful transition, but predominantly from the perspective of healthcare professionals or parents (Paine et al, 2014, Wright et al, 2014 and Sebastian et al, 2012). To date, no high-quality study has exclusively

investigated the opinions of young people with IBD themselves. Fegran et al (2014) conducted a qualitative metasynthesis of studies that investigated transition experiences of adolescents and young adults with chronic diseases and the findings supported that transition is a challenging phase for them that can be associated with feelings of not belonging or being redundant. While their study explicitly focussed on the view of adolescents rather than professionals and parents, it looked at transition experiences across chronic conditions and the metasynthesis did in fact not include an IBD population study. While Fegran et al's (2014) study suggests that transition experiences of young people are comparable across diagnoses and cultures, it would still be advantageous to investigate transition experiences in young people with IBD. A West of Scotland Paediatric Gastroenterology, Hepatology and Nutrition (WoSPGHaN) work group conducted focus groups with parents and adolescents from WoSPGHaN IBD, liver, nutrition and coeliac services to investigate their views on transitional care both pre- and post- transition. Themes identified through thematic analysis in both pre- and post-transition adolescent groups revealed that adolescents felt they had physically, mentally and emotionally outgrown children's services but that they felt their parents were often not ready for the change. However, while the study explored service-users' views on transitional care, it did not investigate young people's healthcare transition experiences in the context of the coinciding developmental and psychosocial transitions they experience. The study was further limited as it did not employ audio recording and verbatim transcription, but used a hand scribe which may have subjectively influenced the results (MacDonald, 2014).

## **2. Aims**

While there is a growing awareness around issues related to healthcare transition in IBD, important gaps remain in the understanding of this process from the perspective of young patients themselves. This study therefore aims to explore the experiences of young people with IBD during transition from their perspective, using a qualitative approach. A qualitative approach can capture the complexity of adolescent's subjective experiences that quantitative methods do not always catch and produce in-depth information from which hypotheses can emerge and practice be informed (Fegran et al, 2014).

### **2.1 Objectives**

- To explore the experiences of young people with IBD at this developmental stage during which a number of transitions occur, including healthcare transition
- To explore the needs of young people with IBD during healthcare transition
- To explore participants' viewpoints regarding transitional care

## **3. Plan of Investigation**

### **3.1 Participants**

Participants will be recruited from NHS Greater Glasgow and Clyde (NHS GGC) adult gastroenterology services.

#### Inclusion criteria:

1. Have an established diagnosis of IBD, i.e. Ulcerative Colitis, Crohn's Disease or IBD

unclassified

2. Have completed or are in the process of completing the NHS GGC transition process
3. No more than 24 months have passed since transition was completed
4. Are 16 years and above
5. Fluent in English

#### Exclusion Criteria

1. Known diagnosis of a learning disability
2. On a course of high dose steroids due to a disease flare-up

### **3.2 Recruitment Procedure**

Participants who match the inclusion criteria will be identified by a member of the NHS GGC adult gastroenterology service at Queen Elizabeth University Hospital (QEUH) and contacted by post. The research pack will include an invitation letter, participant information sheet, participant response form (see Appendix A, B and C) and freepost envelope addressed to the researcher at the Institute of Health and Wellbeing, University of Glasgow. Alternatively, potential participants may also be approached and provided with a research pack at clinic appointments. IBD patients transition from paediatric gastroenterology at QEUH to a variety of adult clinics across GGC. QEUH gastroenterology will liaise with local teams to facilitate the distribution of research packs to potential participants who meet the inclusion criteria.

Interested participants will be asked to indicate their decision to participate and consent to be contacted by the researcher to arrange an interview. Interviews will be arranged for a time that is suitable for the participant. Participants will be recruited on a first come basis and recruitment will end when the required number

of participants has been engaged.

Should the response rate be insufficient to meet the required number of participants, a reminder letter will be send out to potential participants within one month of sending out research invitations.

### **3.3 Interview**

A semi-structured interview will be conducted with individual participants. Interviews are expected to last between 45 - 60 minutes and will be recorded using a digital voice recorder. A semi-structured interview schedule containing key questions and probes will be used to guide the interview (see Appendix E). This schedule will be designed through the review of relevant literature and discussion with supervisors and gastroenterology service staff.

### **3.4 Design and Research Procedures**

The study will use a retrospective qualitative design and semi-structured interviews. A qualitative phenomenological approach aims to 'give voice' to and make sense of the concerns of participants (Larkin et al, 2006). It provides rich information on their lived experience and how they make sense of these experiences. Semi-structured interviews allow participants to tell their stories, express ideas and develop reflections at some length which facilitates the collection of rich and detailed data (Smith et al, 2009).

There is a recognised concern that the use of retrospective questions can result in a degree of recall error and that there is a decline in recall accuracy over time. Research however suggests that not all memories decay in time and that more salient life events are remembered better and with greater accuracy (e.g. Smith

& Thomas, 2002; Norris & Kaniasty, 1992; Mathiowetz & Duncan, 1988). The transfer from paediatric to adult care would be a particularly salient event.

### **3.5 Justification of Sample Size**

Based on NHS GGC data records from 2013 to 2016, a pool of about 34 potential participants can be anticipated.

The primary goal of Interpretative Phenomenological Analysis (IPA) is the in-depth examination of certain phenomena rather than the generating of a generalizable theory. IPA studies therefore usually benefit from small sample sizes that permit the detailed analysis of each participant's account (Pietkiewicz & Smith, 2012). Smith et al (2009) propose that four to ten participants are a reasonable sample size for a professional doctorate. Smith & Osborne (2003) recommend five or six as an acceptable sample size for a student project using IPA. These sample sizes are deemed sufficient for the researcher to develop meaningful points of similarity and difference between participants without being overwhelmed by the quantity of data. Sample size is further dependent on the richness of the individual cases and the constraints the researcher is operating under (Smith & Osborne, 2003).

Considering these suggestions as well as the expected pool of participants and the time constraint of the research project, a sample size of a minimum of four and maximum of ten participants is considered acceptable.

### **3.6 Settings and Equipment**

Interviews will be conducted by the principal researcher with individual participants in a private room at the Glasgow Clinical Research Facility (CRF) on QEUEH Campus. Interviews will be transcribed verbatim by the principle researcher, and all person identifiable information will be removed to ensure

participant confidentiality. The recordings will be stored on an encrypted laptop and destroyed on completion of transcription.

### **3.7 Data Analysis**

Data analysis will follow the analytical process of IPA. IPA aims to explore and make sense of the experience of a particular phenomenon and the meanings participants attribute to their experiences. The researcher adopts an ‘insider’s perspective’ (Conrad, 1987) to see what the experience is like from the participant’s view, but also interprets and analyses how the participant makes sense of it. Analysis proceeds in a stepwise manner and involves the researcher’s immersion in the transcript, the development of emergent themes and the search for connections across emergent themes and participants (Smith et al, 2009). A small number of transcripts (n=2) will also be analysed by one of the research supervisors to increase the consistency and coherence of the analysis, and to ensure that the analysis is not confined to one perspective and makes sense to other people (Yardley, 2015).

## **4. Health and Safety Issues**

Interviews will be conducted on an individual basis and during normal working hours. Standard NHS GGC health and safety procedures will be followed. Rooms are fully equipped with emergency call bells and staff are available during normal working hours. No home visits will be conducted.

All participants will receive an information sheet that provides detailed information about the study including the confidentiality of their responses and participants will be advised that they are free to withdraw or to decline answering

specific questions at any time (with no repercussions). At the beginning of the interview written informed consent will be obtained from all participants (see Appendix D). If a participant becomes distressed or upset during the interview process they will be offered a break, reminded that they can withdraw and sources of additional support will be signposted to them. In case suicidal intent is reported, the participant is taken to A&E at QEUH. If suicidal ideation without intent is reported, the researcher will notify the GP and advise the participant to attend their GP surgery (see Health and Safety Form, Appendix F). If risk is reported this will also be discussed with the field supervisor.

## **5. Ethical Issues**

Ethical approval will be sought from the West of Scotland NHS Research Ethics Committee

as well as the Research and Development Department.

Participants will be 16 years and above and per the Legal Age of Capacity (Scotland) Act (1991) able to give consent to take part in this research. Data will be stored and handled in accordance with the Data Protection Act (1998) and the NHS Confidentiality Code of Practice Guidelines (2003). Recordings will immediately be transferred to a University of Glasgow encrypted laptop and deleted from the digital voice recorder. Anonymised transcripts will be stored on the encrypted laptop. On study completion, transcripts and recordings will be transferred to Enlighten for 10 years, as per the Code of Good Practice in Research (University of Glasgow, 2016) and deleted from the laptop.



## 6. Financial Issues

Equipment cost will amount to a digital voice recorder and transcription equipment (to be borrowed from the University of Glasgow), the purchase of NVIVO software and stationery, photocopying and postage costs (see Research Equipment and Expenses Form, Appendix G).

## 7. Timetable

Date	Task/Deadline
December 2016	Submit Draft Proposal
January 2017	Submit Proposal Prepare ethical approval paperwork
February/March 2017	Blind Review of Proposal Draft REC paperwork
March/April 2017	Address marker's feedback and develop final Proposal Continue to draft REC paperwork
May-July 2017	Apply for ethical approval
August/September 2017	Begin Recruitment
October 2017 - February 2018	Interviewing and Analysis
March - May 2018	Write up research
July 2018	Submit thesis
September 2018	Viva

## **8. Practical Applications**

If healthcare professionals have a better understanding of the experiences of young people with IBD as they transfer from paediatric to adult care, services could be designed to meet the needs of the population, thus improving their transition experiences and health outcomes.

## **9. Dissemination**

A copy of the final thesis will be deposited on Enlighten, the University of Glasgow research data repository. Participants can indicate on the consent that they would like to receive a summary of the research findings which will be posted to them within three months of completing the thesis. Dissemination in a peer reviewed scientific journal will be considered.

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